

**HELPING TYPICALLY DEVELOPING CHILDREN  
HAVE SUCCESSFUL PLAY EXPERIENCES WITH A  
SIBLING WITH AN AUTISM SPECTRUM DISORDER**

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## Contents

Table of Tables .....	8
Abstract .....	9
Acknowledgements .....	11
Chapter 1. Introduction .....	12
Chapter 2. Literature Review .....	15
Plan for the Literature Review .....	15
The Needs of Children with ASD .....	15
Increasing the Social Engagement of Children with ASD.....	18
Behaviours that facilitate social engagement in children with ASD .....	18
Advantages of interventions in the children's natural environments.....	21
Close warm relationships enhance children with ASD's development.....	21
Peer Interventions .....	23
Sibling Relationships .....	27
The potential of sibling relationships when one child has ASD .....	27
Sibling relationships when one sibling has ASD .....	28
Requirements for good quality sibling relationships .....	30
The Well-Being of Siblings of Children with ASD.....	33
Family influences on sibling well-being and on the sibling relationship .....	35
Summary of influences on sibling well-being .....	36
TD Siblings' Understanding of ASD.....	37
TD siblings do not have an age appropriate understanding of ASD.....	37

Providing TD children with information about ASD .....	39
The benefits of promoting the TD sibling's emotional knowledge .....	40
Summary .....	40
Ethics of Using Siblings in Interventions .....	40
The potential for distorting the existing relationship .....	41
The potential influence of an intervention on the children's family.....	43
Giving TD siblings the opportunity to be included in the child with ASD's treatment plan.....	43
Social validity .....	44
Interventions that have Focused on Improving Social Interactions between Siblings .....	45
Sibling interventions that use responsive strategies.....	50
Interventions that promoted sibling interactions without training the TD children .....	51
Summary .....	59
Conclusion .....	61
Rationale for the Original Study .....	62
Chapter 3. Methodology Section .....	66
Methodology .....	66
Design .....	66
Unexpected responses to the project.....	67
Assumption 1. That the proposed design met the needs of the families.....	67

Assumption 2. That the proposed design benefited both children.....	68
Assumption 3. That measuring the quantity of changes provided useful information.....	69
Assumption 4. That the siblings' interactions would be better quality if the TD sibling was taught responsive interaction strategies .....	70
Assumption 5. I could control the environment so that the measures measured what they said they would measure. ....	71
Difficulties in comparing the outcome of the project across the participants.....	74
Changes in the Project .....	74
Accounting for the unexpected findings .....	75
The qualitative framework used in this project.....	77
Making the process rigorous .....	77
The use of relevant literature .....	78
Conclusion .....	79
Method .....	79
Participants.....	79
Chloe and Samuel .....	79
Kathryn and Andrew .....	80
Gracie and Grant .....	81
Ezra and Ollie .....	82
Setting .....	83
Procedure .....	83

Intervention Program .....	84
Identifying Findings.....	86
Chapter 4. Findings .....	88
Cluster 1: Findings from the Observation Period .....	89
What the families wanted from the project.....	89
What the TD children wanted from the project .....	91
The relationship between the siblings.....	91
Play between the siblings.....	92
The quality of the sibling's play .....	95
The TD children's existing skills at interacting with their sibling with ASD .....	97
The TD children's understanding of their sibling with ASD's difficulties .....	99
The children with ASD's interest in their siblings.....	100
The siblings interacted together in situations other than play situations .....	101
Cluster Two: The Intervention Phase of the Project.....	102
The TD children's responses to the intervention phase .....	102
Responsive strategies .....	104
Ethical Dilemmas /Challenges in implementing the intervention phase .....	107
The project could harm existing relationships .....	109
Unexpected outcomes could have a negative influence on the TD children .....	109
Developmental influences on the outcomes of the intervention.....	111
Cluster three: Useful Components of the Project .....	112

Positive game experiences increased the likelihood that the children would spend time together .....	112
It was important to find games or activities that both children enjoyed.....	114
Other games and activities .....	117
Providing information encouraged positive attitudes towards their sibling with ASD by the TD children .....	117
The contribution of parents and non-involved siblings to the project .....	119
Cluster 4: Findings from the Final Parent Interview .....	120
Having a person come to the house and work with the TD child was helpful ..	120
Summary of findings.....	124
Chapter 5. Discussion .....	126
Findings on Costs and Benefits to the TD Children from being Involved in a Sibling Intervention .....	126
Outcomes of the Intervention Components .....	129
Participating in the emotion component made the TD children feel special .....	129
Teaching the TD children responsive strategies did not result in the expected enhancement of the children's interactions.....	129
Games and activities .....	131
Information component.....	132
Advantages of embedding the intervention in the natural environment .....	132
The role of adults in the project .....	133
Social validity .....	134

Limitations .....	134
Conclusion .....	135
Further Research .....	137
References.....	139
Appendix A.....	155
Approval Letter from the University of Canterbury Human Ethics Committee ...	155
Appendix B .....	156
Information Letter for Parents .....	156
Appendix C .....	159
Information Letter for TD Siblings.....	159
Appendix D.....	161
Parent Consent form .....	161
School of Educational Studies and Human Development .....	161
Appendix E .....	162
Parent Consent to the Researcher Contacting Professionals Involved with the Children.....	162
Appendix F.....	163
Child Consent Form.....	163
Appendix G.....	165
Personality Profile.....	165
Appendix H.....	167
Personality Profile.....	167

Appendix I .....	169
Table 2 .....	169
Appendix J .....	171
Resources .....	171
Appendix K.....	172
Train and Fairies Game.....	172
Appendix L .....	173
Table 3 .....	173

### **Table of Tables**

Table 1: <i>Interventions that have focused on improving social interactions between siblings</i> .....	53
Table 2: <i>Activities introduced to the children</i> .....	169
Table 3 <i>Parent's answers to post-project scaling questions</i> .....	173



## **Abstract**

Children with autism spectrum disorder (ASD) are shaped and in turn shape the people in their environment especially those closest to them, their parents and their siblings. When the sibling relationships between children with ASD and their typically developing siblings are considered, challenges and opportunities present themselves for both siblings. This study assessed the effectiveness of a sibling intervention that aimed to meet the needs of both siblings involved.

It was initially hypothesised that teaching the typically developing children responsive strategy use would enhance their interactions between the children leading to increases in the quality of the sibling relationship and in the well-being of both siblings. In addition, the typically developing children were given developmentally appropriate information on their sibling's difficulties, information on emotions, and the opportunity to play mutually enjoyable games with their sibling with ASD to enhance their motivation to persist in attempts at interacting with their sibling with ASD.

Initial findings suggested that the planned intervention was not necessarily benefitting the typically developing children. The focus of the intervention changed to include a more explicit focus on the influence of the intervention on the typically developing children. Changes were made, by de-emphasising the strategy component and emphasising the other components, to enable both siblings to benefit from the intervention.

Findings indicated that the typically developing children had existing skills for interacting with their siblings with ASD. Increases in the quality of the sibling interactions and the well-being of both children seemed to be most strongly related to aspects of the intervention that increased the warmth of the children's feelings towards each other and the typically developing children's understanding and tolerance of their sibling with ASD.

Overall, the findings from this project emphasised the importance of supporting family members of children with ASD for the benefit of both the family members and the benefit of the children with ASD.

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## Chapter 1. Introduction

Although it was difficult to teach my brother how to play with others, it would have been easier for my parents or educators to teach me instead. In nursery school, I learned the basics of playing with other children. I did not learn how to play with an autistic child, though. No one taught me. It is something that I regret because my trial and error approach at a young age met with limited success. The times that we did find success were momentous and remain in my mind today as some of the best experiences. (Konidaris, 2005, P.1271).

This project is an attempt to do what Jason Konidaris suggests, to help typically developing (TD) children have successful play experiences with their sibling with Autistic Spectrum Disorder (ASD). The term ASD covers the related developmental disorders of classical autism, Asperger disorder and pervasive-developmental disorder-not otherwise specified in DSM-IV (Ministries of Health and Education [MOHE], 2008). There will be significant numbers of children in New Zealand with siblings with ASD, given that prevalence data suggest that there are approximately 40,000 New Zealanders with ASD (MOHE, 2008).

A number of experiences inspired the idea of focusing on children with ASD, their siblings and the sibling relationship. As part of my studies I attended a music group for preschool children with ASD and their parents. The parents frequently mentioned concerns about their TD children and the difficulties they were having in promoting a quality relationship between their child with ASD and their siblings. I attended a presentation by a number of siblings of children with ASD where I heard firsthand the joys and difficulties of living with a sibling with ASD. These experiences impressed on me the importance of support for the TD siblings of children with ASD and the importance of support for the siblings in their relationship.

The project involved families and children welcoming me into their homes and giving of their valuable time. In order to make it most likely that the project would provide benefits

for the children and their families I included a number of components, with research evidence to suggest that they might improve the play interactions between the children involved, in the project.

It has proved an interesting time to undertake research on the siblings of children with ASD as in recent years there has been a huge amount of research on all aspects of ASD. Although, there are recent reports on sibling interventions for children with ASD (e.g. Tsao & Odom, 2006; Stewart, Carr & LeBlanc, 2007) the current rate of research on ASD means that the rapidly growing literature includes a wide range of findings that are relevant to sibling interventions, all of which need to be considered when designing a sibling intervention.

In addition, there is still much to learn about the lives of the siblings of children with disabilities in general. In the introduction to a special section on the siblings of children with disabilities, in the journal “Mental Retardation”, Hodapp, Giddens & Kaiser (2006) commented that “research on siblings of individuals with disabilities remains underdeveloped” (p. 334). They go on to mention that because people with disabilities are more likely now to be cared for in their family homes than in previous years, their siblings are assumed to be their future caregivers (Hodapp et al., 2006). Given the importance and general longevity of the sibling relationship, helping siblings achieve a good quality relationship when they are children is a worthwhile project.

The differences in the original design for this project from previous sibling interventions were inspired by research on parent- mediated intervention- interventions that involved TD peers and interventions with the siblings of children with developmental disabilities other than ASD (Girolametto, Sussman & Wietzman, 2007; Trent, Kaiser, & Worley, 2005; Zercher, Hunt, Schuler, & Webster, 2001). Working with the children and their families and beginning to understand their perceptions and the reality of their lives lead to a

re-evaluation of the original design. The questions and the focus of the project changed mid way because of this evaluation. However, the purpose of this intervention- to help TD children have successful play experiences with their siblings with ASD- remained unchanged.

## **Chapter 2. Literature Review**

### **Plan for the Literature Review**

The purpose of this project was to help TD children and their siblings with ASD experience pleasurable play experiences together in order to benefit both the child with ASD and their TD sibling. Children with ASD have difficulties in communication and in social skills, and difficulties in thinking and behaving flexibly (MOHE, 2008). These difficulties influence their interactions with others and therefore, the lives of those closest to them.

This literature review will examine literature on the needs of both siblings, on how their needs can be met, on sibling relationships and on sibling interventions that focus on social interactions, to identify the type of sibling intervention that is likely to be most efficacious for both children. The literature review will be organised in sections. The first section will be on the child with ASD's needs followed by research on what best meets their needs. The second section will focus on sibling relationships and the potential of the sibling relationships where one sibling has ASD. The third section will be on research on the well-being of the TD sibling. The final section will focus on sibling interventions, and will include a discussion on the ethics of sibling interventions and a review of previous sibling interventions.

### **The Needs of Children with ASD**

Children develop the characteristic deficits of ASD due to the interaction of neurological, biological, and environmental factors, which vary from child to child (Dawson, 2008; Wetherby & Woods, 2008). Although, the complex and heterogeneous nature of ASD means that the individuals with ASD vary considerably in their abilities, many researchers believe that they may share a reduced motivation to engage in social interactions

(e.g. Dawson, 2008; Gustin, Burgess & Monfort 2007; Wetherby & Woods, 2008). This deficit in social motivation results in atypical interactions and a lack of the appropriate social experiences needed for healthy development. The effects of the lack of appropriate social experiences are both cumulative and cascading (Wetherby & Woods, 2008).

A lack of joint attention, compared to other children, is considered to be the most sensitive discriminator of children with ASD from other children (Dawson et al., 2004). Children with ASD are less likely to respond to other's attempts at sharing joint attention and are less likely to initiate joint attention than other children (Bono, Daley & Sigman, 2004). The skills needed to request help and objects from others are similar to the skills needed to engage in joint attention. Requesting help from others is relatively unimpaired in children with ASD, lending support to the theory that their underlying deficit is reduced motivation to engage with others (Whalen & Shreibman, 2003; Vismara & Lyons 2007). A lack of experiences with joint attention disrupts the development of other skills needed for social interaction, such as an ability to understand the perspectives of others (Volkmar, Lord, Bailey, Schultz & Kim, 2004).

The imitation skills of children with ASD are also delayed compared to TD children (Ingersoll, 2008). Research suggests that children with ASD's imitation deficits may also be due to an underlying deficit in the motivation to engage with other people (Ingersoll, 2008). Ingersoll (2008) found that children with ASD's imitating behaviour is more significantly impaired in spontaneous natural conditions, where the desire to engage with another person prompts imitating behaviour, than in structured conditions where compliance to instructions prompts imitating behaviour.

The role of infants' and children's interactions with their environment, in the development of ASD, suggests that it may be possible to alter their environments to compensate for their biological and neurological deficits and to promote typical social



experiences and more typical development (Dawson, 2008). Some researchers believe it may even be possible to prevent the development of ASD “by facilitating early social engagement and reciprocity between the at-risk infant and his/her social partners, it may be possible to prevent ASD in some cases.” (Dawson, 2008, p. 792).

After infancy, relationships and interactions with other children become important for healthy development (Koegel, Koegel, Frea & Fredeen, 2001). The responses of peers to children with ASD contribute to children’s development of social skills (Weiss & Harris, 2001). All children from across the ASD continuum seem to interact less with other children than do TD children (Anderson, Moore & Godfrey & Fletcher-Flinn, 2004; Koegel et al., 2001). Children with ASD make fewer initiations to other children and when they do, these are poorly timed, and unclear. They are often ignored or not noticed (Wolfberg & Schuler, 2003).

Simply being in the same environment as their peers does not promote interaction between children with ASD and their peers (Bass & Mulick, 2007; Koegel et al., 2001; Godfrey, Moore, Fletcher-Flinn & Anderson, 2002; Anderson et al., 2004). Anderson et al. (2004) observed 10 children with ASD in kindergartens and primary school playgrounds. They found that between 83 and 100 percent of the interactions of the children with ASD were with adults not children. TD children in kindergarten settings have been observed to interact with adults between 2 and 22 percent of the time (Ballard as cited in Anderson et al., 2004 p.381).

The play of children with ASD lacks variety and spontaneity and they are unlikely to be rewarding playmates (Boucher & Wolfberg, 2003; El-Ghorouray & Romanczyk, 1999; Strain, Schwartz & Bovary, 2008). Play is important in developing children’s social skills, leads to friendships, and is a driver of development (Jordan, 2003, & Wolfberg, & Schuler, 2003). Increased participation in play is an important need of children with ASD. “In children

with autistic spectrum disorders, interactive play uniquely addresses the core deficits of relating and communicating as no other approach can.” (Wieder & Greenspan, 2003, p.426).

Children with ASD need help to discover that social interactions are enjoyable and meaningful (Jones & Carr, 2004). They need an environment that supports them in their interactions with others and promotes their involvement in typical social interactions.

Children with ASD need social interactions, play, and relationships with other children.

The next section of this literature review examines research on ways of increasing children with ASD’s social engagement, participation in typical developmental experiences, and interactions with their peers.

## **Increasing the Social Engagement of Children with ASD**

### **Behaviours that facilitate social engagement in children with ASD**

There is evidence that certain types of behaviours by the social partners of children with ASD promote children with ASD’s willingness to interact. Wimpory et al. (2007) investigated which adult behaviours preceded episodes of social engagement in natural play in a clinic-based assessment with 22 preschool children with ASD. They found that the children with ASD were more likely to engage when the adult provided an active input; when their actions followed the child’s focus of attention and continued the child’s focus of attention; and when they imitated the child in a repetitive way (Wimpory et al., 2007).

The study’s findings confirmed the findings of previous studies in that the adult input that aided the social engagement of typical infants and young children also seemed to best aid the social engagement of children with ASD (Wimpory et al., 2007). They concluded that it seems “that “typical” forms of adult relatedness are helpful, indeed perhaps especially

critical, for development in the “atypical” case of children with constitutional abnormalities in relating to others...” (Wimpory et al., 2007, p.571).

Other interventions have also found that building on the child with ASD’s interests and following their lead increases interactions in children with ASD (Girolametto et al., 2007). Vismara and Lyons (2007), in a child-centred parent mediated intervention, used the children with ASD’s perseverative interests to enhance the child with ASD’s motivation to interact. The children’s rate of initiating joint attention increased significantly as a collateral response to the intervention and all the children generalised their initiating joint attention behaviour to other interests besides their perseverative interests (Vismara & Lyons, 2007).

Siller & Sigman’s (2002, 2008) longitudinal study found evidence that the level of synchronisation (matching behaviours to infants’ behaviour) a parent achieved with their child with ASD influenced the development of the child’s joint attention skills and language. They found that undemanding parental utterances that mapped onto the object that the child was attending to was the strongest predictor of the child’s language gains over 1, 10 and 16 years. Undemanding utterances which followed the child’s attention were predicative of better outcomes than demanding utterances that required the child to change their activity (Siller & Sigman, 2002; Siller & Sigman, 2008). In addition, they identified that the parent’s rate of pointing out an object the child was already attending to was positively related to the child’s gain in initiating joint attention over 1, 10 and 16 years (Siller & Sigman, 2002).

Siller & Sigman (2002) concluded that children with ASD might require higher levels of synchronisation in interactions for optimal development. Doussard-Roosevelt, Bazhenova & Poorges (2003) compared the maternal approach behaviours of 24 mothers to their children with ASD to that of 24 mothers to their TD children. They found that there were qualitative differences between the two groups as the mothers individualised their approaches to their children’s needs and abilities. For example, they observed that the mother’s approach

behaviours differed according to the language abilities of their children. They found that high intensity, close proximity, and nonverbal object use helped stimulate interaction between a mother and her child with ASD (Doussard- Roosevelt et al., 2003). They also found that the type of approach used to engage a child with ASD seems to be more critical to the success of the attempt than it is with TD children (Doussard-Roosevelt et al., 2003).

It seems that it is particularly important that a social partner follow the lead of a child with ASD. Doing so means that the child with ASD is not required to change their focus of attention and their existing motivation is captured and enhanced. By promoting the child with ASD's engagement with others, the use of responsive behaviours increases the child with ASD's opportunities to be involved in interactions and activities that promote their development (Kim & Mahoney, 2004). Following the child with ASD's lead and using a non-demanding responsive approach requires the child's social partner to adapt their interactive behaviour to the child's developmental level promoting the potential occurrence of scaffolding within interactions (Abrendroth, 2008). Interventions that have promoted parents' responsiveness have found increased engagement in social interactions by the child with ASD and increased vocabulary in the child with ASD (e.g. Girolametto, et al., 2007; Mahoney & Perales, 2005).

It seems that to promote social interactions in children with ASD, their partner in the interactions behaviour needs to be particularly responsive to the child with ASD's behaviour (Doussard-Roosevelt et al., 2003; Siller & Sigman, 2002; Wimpory et al., 2006). Research findings that children with ASD respond to the same sorts of experiences as TD children and other children with disabilities emphasises that "children with ASD are children first" (Strain et al., 2008 p. 261).

### **Advantages of interventions in the children's natural environments**

Children's experiences in their daily lives, in their natural settings and with the people in their environment influence their development. The MOHE (2008) guidelines state that the "ultimate aim" of interventions is to promote positive change in the child with ASD in their natural setting. By embedding interventions in children's natural settings, and having them mediated by significant people in their lives, there is no need for the child to transfer learning from one setting to another and from one set of people to another set of people (Rogers, 2000). Children with ASD have trouble generalising learning from one environment to another (Volkmar et al., 2004). "The most entrenched challenge to interventions in autism is the core difficulty with generalization of skills, from explicit and structured settings to naturalistic environments" (Volkmar et al., 2004 p. 144).

Families frequently do not participate in interventions because of access and scheduling difficulties (Birkin, Anderson, Seymour & Moore, 2009). Home based interventions are likely to be more accessible for family members. Working with the children in their home-based environment may support the power of parents (Dunst & Dempsey, 2007). Placing interventions in the child's natural environment provides an opportunity to help family members learn how to mediate an intervention in the real world with its multiple challenges. In addition, interventions embedded in the child's natural environment allow an intervention to build on the child's existing significant relationships.

### **Close warm relationships enhance children with ASD's development**

Researchers have found evidence that close warm relationships enhance children with ASD's development (Yoder & McDuffie, 2006). The use of child-centred responsive behaviours by caregivers and other people in the child's environment help build close warm relationships. Research on the relationship between caregiver's behaviour and child outcomes has found that responsive behaviours by caregivers facilitates social and communication

development in TD children, children with disabilities other than ASD and children with ASD ( Mahoney & Perales, 2003; Mahoney & Perales, 2005; Mahoney, Weeden & Perales, 2004; Siller & Sigman, 2002; Tomasello & Farrar, 1986).

In a study on children with disabilities, the majority of whom had ASD, maternal responsiveness and affect was more strongly associated with the child's level of engagement in play than their developmental status (Kim & Mahoney, 2004). Other research has found attachment levels to be a better predictor of play than diagnosis or developmental level (Naber et al., 2008). These findings suggest the important influence of the quality of children with ASD's relationship with their primary caregiver in helping them play.

Mahoney et al. (2004) compared the influence of types of instruction at preschools on children with developmental disabilities, a third of whom had autism, and the influence of maternal behaviour on the children's development. The instructional styles spanned the continuum of instructional styles for children with developmental disabilities. Mahoney et al. (2004) failed to find a relationship between the type of instruction the children received at the preschool and their development. However, they did find a significant relationship between maternal behaviour and the children's development (Mahoney et al., 2004).

Not all research has found evidence for the influence of parental behaviour. Van Ijzendoorn et al. (2007) found no relationship between parental sensitivity and the attachment status of children, mean age 28.4 months, using the Strange Situations assessment. They did find a relationship between the severity of the child's social deficits and lack of attachment suggesting that responsive parenting has less influence on a child with ASD's deficits when their deficits are more severe (Van Ijzendoorn, et al., 2007). These results may have been because the typical sensitive parenting they measured may have been too "low key" for children with ASD. The results may reflect the increased need for parents of children with ASD to match their parenting to their child with ASD's needs. In addition, it might take

longer for sensitive parenting to result in an attachment relationship with the child with ASD (Van Ijzendoorn, et al., 2007).

Overall research on close warm responsive relationships for children with ASD suggests that the importance of high quality relationships for children with ASD's development. Research has identified that family involvement is a key component of all types of effective interventions for children with ASD (National Research Council, 2001). These findings support the importance of enhancing the child with ASD's relationship with their family members and of supporting the family of children with ASD.

Most of the above evidence (of behaviours and relationships that increase the social engagement of children with ASD) is from research that examined the interactions between adults and children with ASD. The following section examines the interactions of TD children with children with ASD and research evidence on how TD children can promote the development of children with ASD.

### **Peer Interventions**

It is important for children with ASD's optimum development that they have social interactions and relationships with peers. Although adults can mediate interventions for children with ASD, adult mediated interventions do not answer the child's need for interactions with other children, and children with ASD are unlikely to use skills learnt with adults with their peers (Rogers, 2000). Interventions that aim at increasing children with ASD's interactions with their peers need to involve their peers and to take place in the children's natural environment (Rogers, 2000).

Peer interventions motivate TD children to interact with their peers with ASD and to prompt and reinforce children with ASD in social interactions (Bass & Mulick, 2007). A considerable amount of research on the use of peer-mediated approaches with children with ASD has demonstrated that the use of peers as mediators can result in increased social

behaviour by the child with ASD. “Peer-mediated approaches represent the largest and most empirically supported type of social intervention for children with autism” (Bass & Mulick, 2007, p. 728).

The roles TD children take in peer-mediated interventions have been described as “artificial” as their behaviour with the children with ASD is partially directed by adults (Wolfberg & Schuler, 2003). Adult prompting and praise, and tangible reinforcers, have generally provided the incentive and motivation for TD children to persist in attempts to interact with their peers with ASD (Bass & Mulick, 2007). Peer-mediated interventions are complex and to achieve results they need to be implemented with integrity (Strain et al., 2008). “Implementation of such approaches is complex, they require socially skilled typical peers, and they necessitate adults to train peers, control rates of reinforcement, and record data” (Bass & Mulick, 2007, p. 730).

The following example demonstrates the vulnerability of interventions where children’s participation is prescribed by adults and reliant on external reinforcement. Chung et al. (2007) found that infrequent verbal praise from adults did not provide adequate motivation for TD children to participate fully in a peer-mediated social skills intervention. “In this training, peers were asked to pay attention to target children’s responses and continuously prompt communication. Verbal praise was provided only intermittently. This was often difficult even for socially skilled peers. Some peers became bored or frustrated, which impacted target children’s communication frequency and quality significantly” (Chung et al., 2007, p.435).

In some peer interventions, adults facilitate mutually enjoyable peer play. One example is the integrated playgroup approach where small groups, consisting of TD children and children with ASD, meet regularly to play together (Wolfberg & Schuler, 2003). The TD children are familiar peers of the child with ASD (Wolfberg & Schuler, 2003). Zercher et al.



(2001) applied the integrated playgroup model in a community setting. There were five members of the group, twin 6 year-old boys with ASD and three TD sisters, ages, 5, 9 and 11. The three girls were guided by an adult facilitator to prompt play with the boys, extend the play and to persist in their efforts with the boys. After the coaching stopped the girls continued using the strategies they had been taught providing evidence that children can implement strategies without direct adult guidance (Zercher et al., 2001). The intervention resulted in “dramatic” increases in joint attention, pretend play and communication by the children with ASD (Zercher et al., 2001). The parents of the children with ASD commented that their children were playing like “normal” children when they watched a videoed play session (Zercher et al., 2001).

Koegel, Werner, Vismara, Koegel (2005) investigated the use of mutually reinforcing activities and adult facilitation on primary school aged children with ASD’s interaction with a TD peer. The peer was invited to the child with ASD’s house or some other community setting to play with them. The interests of both children were considered in choosing activities for the children and the adult facilitator arranged the activities so that the children needed to cooperate with each other to participate in the activity. In this intervention, the TD children were not guided in their behaviour with the child with ASD. Instead, the facilitator set up play so that there were roles for both children in the play activities.

There was a control condition in which the opportunities for play were the same but there was not contextual support. There was little social interaction between the children in the condition without the contextual support. In the contextual support there were high levels of unprompted social interaction (Koegel et al., 2005). Both the TD children and the children with ASD demonstrated higher levels of enjoyment in contextually supported condition. After the contextually supported condition, the children with ASD received their first invites

from peers to play at their houses. This indicated the possibility that peers' attitude to the children with ASD had changed (Koegel et al., 2005).

Peers involved in successful peer interventions report positive personal outcomes such as improved self-concept and increased tolerance (DiSalvo & Oswald, 2002). DiSalvo & Oswald (2002) identified that the TD children's negative expectancies, of children with ASD as playmates, change in successful peer interventions. They suggested that an active ingredient in successful peer interventions may be the changing of such expectancies in the TD children (DiSalvo & Oswald, 2002).

Research on peer interventions demonstrates that TD children can learn to promote interaction with children with ASD. Research evidence suggests that for TD children to follow adults' directions and guidance on ways to interact with children with ASD there generally needs to be some external reinforcement. There is evidence that mutually enjoyable play can provide motivation for both TD children and children with ASD to interact although mutually enjoyable play may require adult facilitation (Koegel et al., 2005). In addition, there is evidence that the expectancies held by TD children can be changed by their involvement in peer interventions resulting in improved attitudes towards children with ASD and improved motivation to interact with them (Disalvo & Oswald, 2002).

Unfortunately, there is a lack of evidence that peer interventions result in significant maintenance and generalisation of such improvements (DiSalvo & Oswald, 2002). Strain & Schwartz (2001) in a review of peer interventions concluded that although peer interventions increase the social behaviour of children with ASD and achieve positive results, they have not yet resulted in meaningful life style changes. The limited impact of peer interventions are probably because of the lack of an existing relationship prior to an intervention, the limited time involved and the transitory nature of most relationships between a child with ASD and an unrelated peer (Strain et al., 2008). Interventions using siblings do not share these

limitations .The following section discusses the potential of TD siblings to help meet the needs of their siblings with ASD.

### **Sibling Relationships**

For most people, sibling relationships are unique and important relationships. They are the only relationships that are likely to endure throughout a person's lifetime. The emotional ties between siblings are generally only second to the tie between child and parent (Rivers & Stoneman, 2003). Brothers and sisters spend more time together than they do with either their parents or their peers. Siblings begin as play partners and are generally the most consistently available peer(s) to play with throughout childhood (Celiberti & Harris, 1993; Orsmond & Seltzer, 2007).

After reviewing current findings on sibling relationships, Dunn (2005) concluded: "The message is that we simply cannot ignore the significance of siblings with regard to both adjustment problems and positive development; to understand the influence, we must take full account of the quality of the relationship" ( p.655). Dunn (2005) raises two points, the first being that siblings have the potential to influence each other's development both positively and negatively, and the second that the quality of their relationship with each other mediates the influence they have on each other.

### **The potential of sibling relationships when one child has ASD**

Sibling relationships unlike other peer relationships do not rely on children having the skills to establish and maintain friendships (Orsmond & Seltzer, 2007). As children with ASD have deficits in these skills, siblings are frequently their only close peers (El-Ghoroury & Romanczyk, 1999). McElwain & Volling (2005) found that a good quality sibling relationship could compensate for poor quality peer relationships and vice versa, as both

relationships provide opportunities for children to learn about other children and to develop social skills.

Interactions with siblings, especially with siblings who are older, contribute to children's social and cognitive development (Knott, Lewis & Williams, 2007). Older siblings, as young as 5 years old, use strategies with their younger siblings that scaffold the younger child's learning in a similar fashion to the way parents scaffold their children's learning (Klein, Feldman & Zarur, 2002). For TD children, having siblings available for pretend play activities is especially important in the development of an understanding of others' mental states (Fongay, Gergely & Target, 2007). There is evidence that having a good quality relationship with one or more older siblings has a positive influence on children's performance on false-belief tests, which assesses the child's ability to see the world from another's perspective (Carpendale & Lewis, 2004). This suggests that, playing with older siblings, with whom they have a good quality relationship, might improve the ability of children with ASD to understand the perspective of others.

### **Sibling relationships when one sibling has ASD**

Research indicates that sibling relationships, when one child has ASD, are different from that of typical sibling relationships. However, being different does not equate with being inferior (Stoneman, 2001). In sibling relationships when one child has ASD, TD siblings have been observed, to take on the behaviours that encourage and prolong interactions (Knott, Lewis & Williams, 1995 & 2007).

The TD siblings use behaviours with their siblings with ASD that are typically used by siblings with each other. However, in TD sibling dyads birth position strongly influences the behaviours used by a child, whereas in a sibling dyad with a child with ASD the behaviours of the children are strongly influenced by their developmental status (Knott et al., 2007). An example is that in TD sibling dyads, the younger sibling does most of the imitating

to maintain the interactions, whereas Knott, et al. (1995) observed that in sibling dyads, where one sibling had ASD, the TD sibling imitated their sibling more than their sibling with ASD imitated them, irrespective of their birth position.

Knott et al. (1995 & 2007) observed sibling interactions in sibling dyads where both children were TD and in sibling dyads where one child had either Down syndrome or ASD. Although Knott et al. (1995) observed less interaction between siblings when one sibling has ASD than in the other sibling dyads, play between the siblings still occurred for an average of 40 minutes of every hour the siblings were together at home.

Knott et al. (2007) recorded sibling dyads interacting for an hour, at two points in time, a year apart. They found that although the rate of interactions increased between the siblings over the 12-month period, as would happen with siblings who were TD, it was the TD children who stage-managed the interactions with the response rate of the children with ASD remaining stable (Knott et al., 2007). The increase in the rate of initiations by their siblings resulted in an increase in the number of responses by the children with ASD. The children with ASD's rate of imitation of their sibling had increased at the second measure and they appeared to show more interest in their siblings and social engagement with their siblings then too (Knott et al., 2007).

Knott et al. (2007) observed that children with ASD used skills with their siblings that they have rarely been observed to use with peers. They concluded that "With their siblings at least, children with autism appear to develop in line with other children, albeit more slowly. Their ability to engage in collaborative interaction appears to be uniquely enhanced by the role reciprocity inherent in the sibling relationship" (Knott et al., 2007, p. 1994).

Evidence that children with ASD's play with their siblings is superior to their play with other children, and the availability of siblings for play, suggests the importance and

potential of the sibling relationship in providing typical peer social interactions to children with ASD (Knott et al., 2007; Orsmond & Seltzer, 2007).

### **Requirements for good quality sibling relationships**

Although Knott et al. (2007) found that TD siblings alter their behaviour to help their sibling with ASD, other researchers have found evidence that TD children's willingness to interact with their sibling with ASD is often reduced because of the unresponsive and unrewarding behaviour of the child with ASD (Boucher & Wolfberg, 2003; Celiberti & Harris, 1993; Doussard- Roosevelt, 2003). Researchers have found less warmth and less conflict between siblings where one sibling has ASD, which may be due to reduced interactions between the siblings (Kaminsky & Dewey, 2001).

The behaviour of the TD children with their sibling with ASD is influenced by the personal qualities and beliefs of the TD child. Rivers and Stoneman (2008), using parent and sibling report on 50 families with an autistic child, investigated the association between siblings' temperament and the quality of their relationship in sibling dyads. They found that the persistence level of the TD child influenced the quality of the sibling relationship. A TD child with high persistence levels is less likely to be discouraged by their sibling with ASD's low and slow rate of responding and will persist in attempts to engage with the child (Rivers & Stoneman, 2008).

Gousmett (2006), surveyed the siblings and parents of 19 children with developmental disabilities, 10 of whom had ASD. The study found a positive relationship between the TD child having a positive self-concept and the quality of the sibling relationship. Gousmett (2006) study did not find evidence for the direction of the relationship between the TD child's self-concept and the quality of the sibling relationship. One possible mediating factor is the TD child's feelings of competency in coping with their sibling's difficulties.

El-Ghoroury and Romanczyk (1995) compared the play behaviours of parents and children with ASD to the play behaviours of TD children with their siblings with ASD using home observations. They found that parents made many attempts to interact with the child with ASD. The TD children made far fewer initiations to their sibling with ASD than their parents, although their rate of physical interactions with their siblings was similar to that of their parents. Parents' behaviour was more organising and intensive whereas the siblings approach was more natural. "Siblings appear to be approaching the observed interactions with children in a manner similar to a typical play situation rather than a teaching situation." (El-Ghoroury & Romanczyk, 1999, p. 256).

The children with ASD, in El-Ghoroury & Romanczyk's (1999) study, made more initiations towards their siblings than they did to their parents. There are a number of possible reasons why they made more initiations to their siblings. Their parents' more intrusive and intensive behaviour may not have allowed the child with ASD opportunities to make initiations to them (El-Ghoroury & Romanczyk, 1999). Children with ASD may have been more comfortable with their siblings' more natural behaviour towards them or they may have wanted to interact with other children.

Anderson et al. (2004) observed 10 New Zealand children with ASD's behaviour during free playtime in schools and kindergartens. They found similar patterns with adults taking a more active role in interacting with a child with ASD, but with the child with ASD making more initiations to other children when interacting with them, than they did to adults in turn (Anderson et al., 2004).

The parents' behaviour in the study may have led to the siblings having fewer opportunities to interact (El-Ghoroury & Romanczyk, 1999). Anderson et al. (2004) observed two different types of adult behaviour during interactions with children with ASD. The first type they described as compensatory behaviour where the adult assisted the child with ASD

to achieve something. They found that adults' use of compensatory behaviour reduced opportunities for interactions between the child with ASD and other children (Anderson et al, 2004). Other children did not become involved in these interactions. The other behaviour they described as facilitative behaviour where the adult scaffolded the functioning of the child including scaffolding peer interactions (Anderson et al., 2004). Findings that adult compensatory behaviour may discourage play between children with ASD and their peers, combined with findings that adults' use of facilitative behaviours encourages peer play, confirm the important influence adults' behaviour has on children with ASD's interaction with other children. (Anderson et al., 2004; Koegel et al., 2005).

The findings from Knott et al. (2007) and El-Ghororay & Romanczky (1999) both confirm that TD children's style with their siblings with ASD is similar to TD children's style with other children. Both studies found that the siblings with ASD showed interest in interacting with their siblings. This suggests the value of using typical sibling behaviours, and a natural style of interaction, with children with ASD.

Research findings suggest giving TD children support to be persistent, in spite of the child with ASD's atypical responsive behaviour, may help the quality of the interactions between the siblings (Rivers & Stoneman, 2008). Gousmett's (2006) research suggests that encouraging and supporting the TD children's self-concept could enhance the sibling relationship. Finally, research indicates that adults' use of facilitative behaviour with children with ASD may encourage interactions between the child with ASD and other children. The above findings suggest the importance of providing support to the TD children, to enhance their motivation to interact and persist in their interactions with their siblings with ASD.



The following part of the literature review considers what TD siblings of children with ASD need for their well-being. The literature review concludes with an examination of research on previous sibling interventions.

### **The Well-Being of Siblings of Children with ASD**

Research on the well-being of siblings of children with ASD have reported contradictory results, with some research finding that siblings of children with ASD have elevated rates of problems and social difficulties and some research finding that they do not differ from other children (Benson & Kurlaf 2008; Orsmond & Seltzer 2007; Orsmond & Seltzer, 2009). It is still an under-researched area (Orsmond & Seltzer, 2009). The heterogeneity of the population, the different age groups, measures, and comparisons used in studies may explain the contradictory report findings (Orsmond & Seltzer, 2009).

There are other possible reasons for these contradictory findings, such as the transactions between different variables in the children's lives. Having a sibling with ASD may make the child more vulnerable to the negative effect of other factors in the child's life. This is possibly because the occurrence of risk factors may make it more difficult to cope with a child with ASD (Macks & Reeves, 2006; Orsmond & Seltzer, 2009). Macks & Reeves (2006) found that children with siblings with ASD generally had a more positive self-concept than other children but were more vulnerable to demographic risk variables.

There is, however, ongoing debate over what are the demographic risk factors for the siblings of children with ASD. Macks and Reeve (2006) identified these risk factors: i) families with only two children; ii) being the older sibling; iii) low annual income; and iv) the TD child being female. Some research has found that being younger than the child with ASD rather than older is also a risk factor (Hastings, 2003; Petalas, Hastings, Nash, Lloyd & Doewy, 2009). Hastings (2003) found that the TD child being a boy was a risk factor. In

addition, some research has found that coming from a large family can be a risk or a resilience factor depending on other variables (Dodd, 2004). Recent research has identified having a brother with ASD as a risk factor for decreased sibling well-being (Petlas et al., 2009).

Having a sibling with ASD may create emotional needs for children. Children in families where one sibling has autism often experience differential parenting with the disabled child being favoured (Rivers & Stoneman, 2008). Most TD siblings experience jealousy or resentment due to the extra attention the child with ASD receives (Hutton & Caron, 2005; Phelps, Hodgson, McCammon & Lamson, 2009). When a child perceives differential parenting and they do not understand the reasons for the differential parenting, it is a risk factor for behavioural and emotional difficulties (Orsmond & Seltzer, 2007). Rivers and Stoneman (2008) found a strong association between the TD children's dissatisfaction with receiving differential parenting and the relationship they had with their sibling with ASD.

Siblings of children with ASD may need help to understand why they are treated differently from the child with ASD. When children perceive the reason for differential parenting and accept it as fair, their relationship with their sibling is not negatively affected (Rivers & Stoneman, 2008). Gold (1993) found that the siblings of children with ASD who have no one to talk to about having a sibling with ASD scored significantly higher on the Children's Depression Inventory (CDI; Kovacs, 1980-1981) than those who had someone to talk to about their sibling. Gold (1993) research results suggested that the siblings of children with ASD had a high risk of depression.

Some siblings of children with ASD may be at higher risk of problems because they have Broader Autism Phenotype (BAP): mild autistic like symptoms, or symptoms of other non-medical disabilities or disorders (Benson & Kurlof, 2008; Toth, Dawson, Meltzoff,

Greenson & Fein, 2007). There is evidence that the family of children with ASD have an increased genetic risk of BAP, although being raised with a sibling with ASD or by a parent who has some ASD symptoms may also contribute to the increased rate of BAP and other disorders amongst the siblings of children with ASD (Orsmond & Seltzer, 2007). Benson & Karlof (2008), in a large study, found that siblings who did not have a pre-existing disability did not have an increased risk of psychosocial problems compared to the general population. Orsmond & Seltzer (2009) found that adolescent female siblings identified as having mild autistic like symptoms were more vulnerable to risk factors.

### **Family influences on sibling well-being and on the sibling relationship**

Having a child with ASD stresses families and influences family function, which in turn influences the child with ASD's behaviour. The severity of the child with ASD's disability is correlated with the stress levels of their parents and of their siblings (Baker-Ericzon, Brookman-Frazee & Stahmer, 2005; Giallo & Gavidia-Payne, 2006; Orsmond & Seltzer, 2009; Stoneman, 2005). Family conflict increases the severity of children with ASD's anxiety and depression problems and their ASD symptoms (Kelly, Garnett, Attwood & Peterson, 2008).

Hastings (2007) found no evidence, in mother's reports, to suggest that having a sibling with ASD put a child at greater risk of an adjustment problem. However, he found evidence that the behaviour problems of the child with ASD put their siblings at risk of behaviour adjustment problems (Hastings, 2007). Research suggests that young children with ASD develop maladaptive behaviour patterns more frequently than TD children (Hartley, 2008). Maladaptive behaviour patterns in children with ASD have been found to contribute to parent's stress and mental health and to family functions (Herring et al., 2006).

Davis and Carter's (2008) research, based on 54 families of young children with ASD, found that almost half of the parents studied experienced clinically significant levels of

depressive symptoms or parenting stress (Davis & Carter, 2008). Parental stress is likely to affect both their TD children and their children with ASD. Meirsschaut, Roeyers & Warreyn (in press), found that when mothers feel incompetent in their parenting of their child with ASD these feelings spill over into their parenting of their TD children. Although, families with ASD experience significant stressors, research shows that families with children with ASD are frequently very resilient over the long term (Singer, 2007).

### **Summary of influences on sibling well-being**

Although a child with ASD does not necessarily exert a negative influence on their sibling's well-being, having a sibling with ASD does increase the risk of negative outcomes when there are demographic risk factors or conflict and stress in the family (Macks & Reeve, 2006). In addition, having a sibling with ASD increases the risk of having Broader Autism Phenotype (BAP), which makes it more likely that additional risk factors will result in negative consequences (Orsmond & Seltzer, 2009). Ensuring that the siblings of children with ASD have support and someone to talk to is likely to help siblings' well-being (Gold, 1993). Research suggests that it is important that children have an understanding of their sibling's difficulties in order to help them accept and cope with the influence of their sibling's difficulties have on their families' functioning. The links between the stress and well-being of parents, the well-being of the siblings, and the quality of the sibling relationship means that the needs of the parents must be considered when trying to improve the children's well-being.

## **TD Siblings' Understanding of ASD**

### **TD siblings do not have an age appropriate understanding of ASD**

One factor that might influence the TD siblings' motivation to interact and to persist in their interactions with the child with ASD is their understanding of their sibling with ASD's strengths and difficulties. An increased understanding of their sibling's difficulties may help the TD child to understand accept differential parenting and cope with any stresses caused by their sibling's disability (Glasberg, 2000; McHale, Sloan & Simenonsson, 1986; Rivers & Stoneman, 2008). "Positive sibling relationships are enhanced by the siblings having knowledge of the ASD disorder" (MOHE, 2008, p. 67).

Embarrassment by the TD sibling about a sibling with ASD's eccentric behaviour is a common theme in the literature (Benderix & Sivberg, 2007). If a child is easily and clearly able to explain their sibling's difficulties, potentially embarrassing situations may be easier to manage for the child (Harris & Glasberg, 2003).

Research on the knowledge and understanding of children with siblings with ASD has provided evidence that children frequently do not have a reasonable understanding of their sibling's disabilities (Glasberg, 2000). Glasberg (2000) interviewed 63 siblings, age range 5-17 years old, to measure their cognitive sophistication in understanding the concept of ASD. Although older siblings' understanding of their siblings' disability was more sophisticated than their younger siblings, all the children showed less sophisticated understandings of ASD compared to normative data on the development of children's understanding of family illnesses. The children's delayed understanding of ASD may be because ASD is a particularly difficult disability to understand (Glasberg, 2000).

Glasberg (2000) found that parents tended to overestimate their children's knowledge. Many children knew the word autism but had very little understanding of what the word meant (Glasberg, 2000). Glasberg (2000) speculated that parents might have told their

children about their sibling's disability but their children may not have understood what their parents were saying and the telling might have been a one-time event.

Although the children's understanding of the implications of their siblings' disabilities were within normal developmental ranges, Glasberg (2000) found that parents "consistently overestimated the child's understanding of its (their sibling's disability) implications" (Glasberg, 2000, p. 153). This suggests that parents may be unaware that their TD children do not understand why some things happen, such as why their sibling with ASD may receive more parental attention or why the family rules are different for their sibling with ASD (Glasberg, 2000).

In contrast, Ross and Cuskelly (2006) had 25 siblings of children with ASD fill in a true or false questionnaire based on DSM IV criteria of autism and Asperger's Syndrome to assess their knowledge of ASD. Their participants' ages ranged from 8-15 years. They found that the children surveyed had a reasonable understanding of their sibling's condition correctly answering an average of 66% of the questions (Ross & Cuskelly, 2006). Research has found that children appear to have a better understanding of sibling's disabilities when the questions used are forced choice, as in Ross & Cuskelly (2006)'s research, rather than open-ended questions (Hames, 2008). It may be that young children's limited vocabulary restricts their ability to express fully their understanding of their sibling's disability when answering open-ended questions (Hames, 2008).

However, limited vocabulary cannot explain why the older children in Glasberg's (2000) study demonstrated less sophisticated understanding compared to normative data on the development of children's understanding of family illness. It seems likely that the different results from the questionnaire and the interviews reflect the different level of knowledge tapped. Glasberg's (2000) interviews may have uncovered more about the sophistication of the children's understanding of their sibling's difficulties. In addition, the

different age ranges may account for some of the difference in their findings as the younger children in her study had the least understanding of their sibling's difficulties. The results from Glasberg's (2000) research suggest that many siblings of children with ASD may benefit from more information on their sibling with ASD's strengths and difficulties.

### **Providing TD children with information about ASD**

There are two types of information about children with disabilities that have been given to children. The first is descriptive information, which emphasises similarities between children with disabilities and TD children and the second type is explanatory information, which gives causal information about why a child behaves as they do. Descriptive information has been shown to improve children's attitudes to a child with a disability (Campbell, 2006). Children are friendly with children who are similar to them rather than different, so to foster friendships it is important to emphasise similarities (Han, Ostrosky & Diamond, 2006).

There are mixed results in the literature on the usefulness of explanatory information about autism in improving children's attitudes towards children with ASD. A number of researchers have failed to find an improvement (Campbell, Ferguson, Herzinger, Jackson, & Marino, 2004). Campbell et al., (2004) found that, in general, the behavioural intentions and attitudes of children younger than 11 improved towards children with ASD when children received both descriptive and explanatory information. Girls' attitudes and behavioural intentions were more likely to improve than boys were. Research has consistently found that girls are more accepting of people with disabilities than boys (Campbell et al, 2004 & Favazza & Odom, 1997). Campbell's research suggests that providing explanatory information can sometimes improve attitudes especially with girls younger than 11.

### **The benefits of promoting the TD sibling's emotional knowledge**

There is research that suggests that the TD sibling's well-being, and the sibling relationship, could be enhanced by providing children with information on emotions in addition to information on their sibling with ASD's difficulties. The "More Fun with Brothers and Sisters Programme", for children 4-8 years old, found that helping children identify and understand their own emotions, and to understand their siblings' perspective, improved children's emotional regulation leading to improved sibling relationship quality (Kennedy & Kramer, 2008). Kennedy and Kramer concluded that, "The current findings suggest that children may benefit if they can develop a rich vocabulary that will enable them to label and make distinctions among different emotions that may be confusing (e.g., distinguishing frustration and disappointment from anger and hate)" (Kennedy & Kramer, 2008, p. 576).

### **Summary**

Helping the siblings of children with ASD identify and label their emotions may help them to regulate their own emotions when trying to interact with an unresponsive and unpredictable playmate and lead to an improved sibling relationship. Improved understanding of their siblings with ASD difficulties could help children understand and accept the dynamics in their own family, especially differential parenting, and may result in the TD children being more inclined to persist in their interactions with their sibling with ASD.

### **Ethics of Using Siblings in Interventions**

The ethical issues of using children in interventions are rarely discussed in the literature (Matson, Matson & Rivet, 2007). This section of the literature review considers some of the ethical issues of using siblings in interventions.



An important ethical consideration is whether children feel able to say “no” to being involved in an intervention. In peer interventions, children can volunteer to be involved whereas in sibling interventions children are generally invited to be involved. The parents of children with ASD are more likely to be keen and supportive of their TD children being involved in an intervention than parents of a child unrelated to the child with ASD (Reagon, 2006). Children may feel pressured to please the adults requesting them to be involved (Matson, Matson & Rivet, 2007). It is possible that siblings of children with ASD will feel that by saying no to involvement in an intervention with their sibling that they are disappointing the adults in their lives.

It is important that the TD children who are working with their siblings with ASD are supported and encouraged by their parents and that the expectations of their parents and those working with them are developmentally appropriate and realistic (Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006). In most peer interventions, the children approached to be involved are chosen carefully. They are usually the more socially skilled children (Bass & Mulick, 2007). It is possible that some siblings of children with ASD will be less socially skilled than other children of the same age due to being raised with a sibling with ASD, or having a parent who has some ASD symptoms or having some mild ASD symptoms themselves. Children may find it difficult to fulfill the expectations of their parents and others involved in an intervention. Consequentially they may feel inadequate.

### **The potential for distorting the existing relationship**

Some of the behaviours the TD children are taught to use may distort the existing sibling relationship. Research, such as Mahoney & Perales (2005), demonstrates that the child with ASD’s relationships are more important than the teaching approach taken with the child. This suggests that any interventions that could potentially distort their relationship would be counterproductive. Interventions that cast the TD sibling in a teaching role or

increase the dominance of the TD sibling have been criticised for increasing the asymmetrical nature of the sibling relationships (Trent et.al., 2005). It is also possible that interventions that try to make the sibling relationship less asymmetrical could also cause harm by changing the existing relationship.

It is important that an intervention involving the TD sibling be designed to meet their needs as well as the needs of their sibling with ASD and their wider family. The roles siblings take in their relationship need to be, as Stoneman (2001) says, “mutually acceptable”. If the role the TD child is cast into is not acceptable then the child is unlikely to stay in that role for long and the results of the intervention will not be maintained. An intervention may shape the sibling relationship in ways that the TD sibling does not want. An example would be a situation where an intervention may work at increasing the sibling’s play whereas the TD sibling may be at a stage where they wish to increase play with peers. The TD child may be more interested in improving the quality rather than the quantity of their interactions with their sibling with ASD.

Encouraging TD children to use new strategies may result in the reduction of their use of behaviours that were useful. Some interventions with siblings have required the TD siblings to deliver directive behaviours such as commands and praise, make initiations to their siblings with ASD, organise play, and give feedback (eg. Celiberti & Harris, 1993; Celiberti, 1994; Tsao & Odom, 2007). These directive behaviours are similar to the behaviours that El-Ghoroury & Romanczky (1999) observed parents using with their children with ASD. The children with ASD were more likely to initiate with their sibling, who were not using these behaviours, than with their parents who were using these strategies (El-Ghoroury & Romanczky, 1999).

### **The potential influence of an intervention on the children's family**

In an intervention, there is a danger that some of the control of what is happening in the family moves from the parents to the researcher. All families have different rules and aims and a researcher may encourage behaviours that are not in accordance with the families' rules. The presence and expectations of the researcher is likely to exert a strong influence over the TD child's behaviour so that the child is less likely to behave as they normally would.

Many families have more than two children. If an intervention includes only two children in a family, the possible implications for other children in the family need to be considered. The link between parent well-being, child well-being and the quality of the sibling relationship means that if an intervention increases parent stress levels or negatively impacts on parent well-being, it will not be successful. It is possible, given the link between parent stress levels and sibling relationship quality, that positive changes in the sibling relationship will lead to reductions in parent stress levels.

### **Giving TD siblings the opportunity to be included in the child with ASD's treatment plan**

Although, there are many ethical issues to consider when including siblings in an intervention as members of the family system of the child with ASD, it is important that they be given the opportunity to be included in the child with ASD's treatment plan. It seems that the sibling's role in the families of children with ASD are sometimes overlooked in the literature with many articles on the families of children with ASD failing to mention or consider siblings (e.g. Herring, Gray, Taffe, Tonge, Sweeney & Einfeld, 2006).

Both research on typical sibling relationships and sibling relationships with children with ASD have found evidence that older children or children who are more developmentally advanced do engage in behaviours that enhance the development of their younger sibling or

sibling with a disability (Knott et al., 2007). These findings suggest that it is natural for more developmentally advanced siblings to further the development of their less advanced siblings. There is anecdotal evidence, such as Jason Konidaris's statement at the beginning of this review, that many children are willing to learn new skills to facilitate interactions with their siblings with ASD. Another example suggesting children would like to be trained to help with their siblings comes from Jones, Carr & Feeley's (2006) observations of siblings' behaviour while they were teaching parents strategies to increase the siblings with ASD's joint attention. They observed that the children's TD siblings were copying the strategies they were teaching their parents, and using them with the children with ASD.

### **Social validity**

For an intervention to be worth the costs to the participants and their wider families it needs to address real concerns and priorities of the participants and their families (Foster & Mash, 1999). To use the time of a child there needs to be benefits for the TD child involved, as well as potential benefits for their sibling with ASD. For a child to maintain changed behaviour the results of the behaviour must be reinforcing. The outcomes targeted by interventions for children with ASD need to be the worth the time, money and energy of all involved in the intervention and appropriate to the needs of the child and their family (NRC 2000; Volkmar, et al. 2004).

To be ethical, an intervention must be based on the latest and best research and have the best possible chance of being successful. "Every moment the child spends in therapies that are minimally effective, ineffective, unproven or likely to be harmful, is a moment that he or she could have spent participating in treatment that has a known probability of success..." (Green, 1996, p. 17).

An ethical intervention would support the needs of both children and help them negotiate roles with each other that are "mutually acceptable" (Stoneman, 2001). To do this,

information would need to be gathered about how the sibling relationship and family functions before they begin the intervention. There would need to be collaboration and consultation between the participants, their families and the intervention provider to help the children find roles that are acceptable to themselves and their families.

The reviewed literature suggests that the most ethical approach for a sibling intervention is one that is embedded in the child's natural environment and existing patterns of interactions. When interventions enhance existing patterns, it is likely that participants would find it easier to maintain and generalise change resulting from these interventions. Knott et al., (2007) concluded that, "Interventions grounded firmly in existing interaction (Rogers, 2000) will therefore enhance naturally occurring patterns of interaction, arguably with more success than interventions which are not." (Knott, 2007, p. 1994).

An ethical intervention that targets the sibling relationship would do so by enhancing the existing relationship of the siblings, increasing both siblings' pleasure in their interactions; meet needs of both siblings; and fit with their family's needs and wishes. The reviewed literature suggests that in an effective intervention, outcomes would be mediated through warm close relationships that build on the child with ASD and the TD child's motivation to interact.

Sibling interventions are analysed in the next section with regard to the needs of the child with ASD, needs of the TD children and to ethical considerations.

### **Interventions that have Focused on Improving Social Interactions between Siblings**

There has only been a small number of sibling interventions that have focused on the social interactions between siblings. Celiberti & Harris (1993) taught three children with siblings with ASD how to elicit play and play related speech by the use of praise, play-related

commands and prompts. The TD children were taught to direct and manage the interactions between themselves and their siblings. The siblings showed relatively rapid mastery of the target skills. The experimenter praised the TD children for correct use of strategies and the experimenter highlighted the children with ASD's responsiveness to their sibling's strategy use. The siblings were given a specific collection of toys to play with. They maintained and generalised the skills. Outcomes for the children with ASD were not reported (Luckett, Bundy & Roberts, 2007). The TD children reported feeling more comfortable interacting with their siblings with ASD after the training. Both parents and TD children reported increased interactions between the siblings after the intervention (Celiberti & Harris, 1993).

It is possible that the positive outcomes reported in this study are partly due to other factors than the type of strategies used by the TD siblings. Some of the benefits of this study may have been due to mutual enjoyment experienced by the siblings when they played with the toys used in this study. The TD children's increased comfort in interactions may also be partly due to increased confidence due to the experimenter highlighting the positive influence of their behaviours on their sibling with ASD's behaviours.

In Celiberti's (1993) research, parents trained nine TD primary school aged children in skills to play with their siblings with ASD. The TD children were taught 21 specific skills designed to 1) elicit appropriate play and play-related speech with commands, directives, and requests; (2) reinforce appropriate play behaviours with specific praise; (3) prompt the child when he/she fails to respond appropriately using verbal and physical prompts; and (4) incidentally reinforce the child's spontaneous play behaviours with praise. Parents were instructed to conduct practice sessions with the typical sibling for half an hour every day. The siblings reported that they found some skills such as using behaviour specific praise challenging (Celiberti, 1993).

There was an emphasis in the intervention on encouraging clear communication by the TD sibling to the child with ASD. Celiberti (1993) found that the TD siblings acquired many of the skills taught. Improvements in the play interactions and in the skill level of the child with ASD were not directly measured. However, parents provided anecdotal information that, for many of the sibling dyads, there were increases in the amount of time they played together due to the TD sibling and the sibling with ASD being more interested in playing with each other (Celiberti, 1993).

When parents were surveyed 10 months after the intervention, they reported that there had been a decrease in 13 of the specific skills the children had been taught, 5 skills had increased and 3 skills were at the same level (Celiberti, 1993). The intervention by Celiberti (1993) demonstrates that TD children can learn strategies to enhance their play with their siblings with ASD. The anecdotal evidence gathered suggests that the enhanced skills and confidence of the TD children led to an increased desire of both siblings to play with each other (Celiberti, 1993). This study made significant demands of both the TD child and their parent.

In Strain & Danko's study (1995), three parents taught their children to make persistent social overtures to their siblings with ASD, in structured play sessions, in a designated room in the children's houses. Parents were trained to guide the children to prompt and praise. The intervention resulted in increases in positive initiations and responses, as well as concurrent social behaviours although these behaviours reduced somewhat when the intervention phase was over (Strain & Danko, 1995). Strain & Danko (1995) found that for the children to have positive interactions, the children's parents needed to remain moderately involved in the sessions. Parents reported that both their children enjoyed being involved in the intervention.

In both Strain & Danko's (1995) intervention and Celiberti's (1993) intervention, the focus was on training parents to train the TD siblings. It is possible that the outcomes of the interventions were due to changes in parental behaviours rather than changes in the TD siblings' behaviour.

Tsao & Odom, (2006) investigated whether four TD siblings could learn and use strategies, to promote social interaction, which school peers of children with ASD had successfully used. The four TD children ranged in age from 4 years to 11 years of age, and their siblings with ASD ranged in age from 3-6 years old. As with Strain and Danko (1995), the study took part in a designated room in the house. Tsao & Odom (2006) investigated whether the use of the strategies by the TD siblings would result in increased social participation by their siblings with ASD. They used joint attention as a measure of increased social participation and a measure of social behaviours, which included measures of the social initiations of each sibling. The intervention phase of the study consisted of 10 teaching sessions with the TD children.

Children were taught to establish eye contact, initiate conversation, organise play and provide verbal feedback. The TD children were told to expect some rejection to prevent them from becoming discouraged and encouraged to persist in their attempts to interact with their siblings (Tsao & Odom, 2006). One of the TD children, a 4-year-old girl, decided that she did not want to participate in all the training sessions. The level of social behaviour that the TD children demonstrated towards their sibling with ASD generally increased from baseline and the increase was largely maintained according to the maintenance data. There was only maintenance data for three of the four children (One of the children with ASD became so fascinated with the video camera that filming him became impossible) (Tsao & Odom, 2006). However, these data also show that the children's parents' prompting increased during the



intervention phase and for two of the three children, for whom there was maintenance data, parent prompting continued during the maintenance phase.

During the study, random generalisation probes were administered in different community settings. The TD children generally maintained the same level of social behaviour towards their siblings but the children with ASD were not as responsive to their initiations. The TD children were not taught specific strategies to promote the joint attention behaviour of their siblings with ASD, yet the intervention resulted in strong and positive changes in the children with ASD's responsive joint attention behaviour (Tsao & Odom, 2006). This finding is consistent with the findings that by increasing the motivation of children with ASD to participate in social interaction the development of joint attention can be facilitated (eg. Baker, 2000; Vismara & Lyons, 2007). There was also moderate improvement in the other social behaviours of the children with ASD. The increased social behaviour of the TD children did not result in increases in the children with ASD's initiating joint attention with them (Tsao & Odom, 2006).

The levels of enjoyment the children with ASD displayed in their interactions with their siblings and the quality and quantity of the engagement were measured throughout the intervention as a social validity measure. There were significant positive increases for the children with ASD, which correlated with the significant increases in their levels of joint attention (Tsao & Odom, 2006).

These results, especially the correlation between the increase in enjoyment levels and the increase in joint attention behaviour, also provide evidence for the theory that children with ASD's core deficits can be improved by approaches that increase their enjoyment of their relationships with others. That there was a significant improvement recorded in joint attention but not in the other measure of social behaviour, may be because joint attention is a

skill that precedes the development of other social behaviours (Anderson et al., 2007; Dawson et al., 2004).

The study by Tsao & Odom (2006) provides further evidence that the siblings of children with ASD can learn strategies, and that changes in their behaviour can result in changes in the behaviour of their siblings with ASD. The study does not provide firm findings on whether the TD children's experience of their relationships with their siblings with ASD improved. The finding that parents prompted some of the moderate increase in the TD siblings' social behaviour towards their brother with ASD suggests that the intervention may not have significantly increased the TD siblings' motivation to interact socially with their siblings with ASD.

Stewart et al. (2007) trained a TD sibling to work with her blind mother in implementing a behavioural skills training programme, to improve her fraternal triplet brother with ASD's social skills. The child with ASD was a high functioning child with ASD. The mother and the TD child were successful in their implementation of the programme and the programme achieved positive results for the child with ASD.

The mother reported, three months after the training, that the TD sibling was able to prompt her brother with ASD to make appropriate conversation. Stewart et al. (2007) did not provide information on whether the TD sibling enjoyed being involved in the training programme. Their project demonstrates that parents and siblings can work together on interventions for their siblings with ASD.

### **Sibling interventions that use responsive strategies**

All of the above studies taught the TD children mainly directive strategies. In searches of the literature, no studies were found where the TD children were taught solely non-directive, responsive skills, to use with their sibling with ASD. Trent, et al. (2005) and Trent-Stainbrook, Kaiser and Fey (2007) taught TD children to use responsive strategies with their

siblings with Down syndrome. In both projects, the TD children were taught to imitate the child with Down syndrome and to respond to all verbal utterances of the child with Down syndrome. In both projects, the TD children quickly learnt the strategies and maintained their use. Both projects reported increases in the child with Down syndrome's communication. Trent-Stainbrook, et al. (2007) found that the sibling interactions became more positive and that both siblings seemed to be enjoying their interactions more.

### **Interventions that promoted sibling interactions without training the TD children**

In an intervention by Baker (2000), three sibling dyads were encouraged in a clinic setting to play interactive games that incorporated the sibling with ASD's perseverative interest. The study did not involve either sibling being taught anything other than the rules of a game. The TD sibling did not receive any training and once the child with ASD understood the concept of the game external reinforcers were not used.

The children with ASD were early primary school age and their siblings were between 1 year and 3 years older. In the baseline condition, the children were presented with a number of age appropriate games to use including games that were similar to the game of Bingo. The number of baseline sessions ranged from 13 sessions to 18 sessions. All three dyads were observed during these sessions to have very low interaction rates (Baker, 2000).

For the intervention sessions, the game Bingo was altered to incorporate the child with ASD's perseverative interests. One child was excessively interested in movies, so the cards for the Bingo game had instructions on them that referred to a place in a specially constructed tape of various movie clips. Another child's interest was crashing cars, so a ramp was constructed that allowed cars, to crash on random Bingo numbers (Baker, 2000). An intervention provider taught the siblings how to play the game and prompted them to play until they could both competently play the game. There were no prompts from adults in the

maintenance or follow up phase. The maintenance and follow up conditions were the same as the conditions in baseline except that the specially altered game of Bingo was also available.

The intervention increased the positive social interaction between the siblings, and the positive outcomes of the intervention were maintained in the 1 month and 3 month follow up sessions. The children with ASD's ritualistic behaviours around their perseverative interests decreased, and their play with their siblings generalised to other games and interests that did not incorporate their perseverative interests (Baker, 2000). The children with ASD showed improvements in joint attention and spontaneous play; for example both TD siblings and the siblings with ASD were observed to covertly cheat in games, this suggested that they understood the game, wanted to win, and could be flexible in their behaviour in order to win (Luckett, et al., 2007).

The children with ASD were motivated to play and showed a level of competence in the games that they seldom showed in other situations. The TD children reported after the intervention that they were more likely to ask their sibling to play than they were before the intervention (Baker, 2000). The children's scores for happiness and interest increased from the baseline phase to intervention, through maintenance and on to the follow up phase. The increase in enjoyment of both children correlated with increases on other measures.

This study provides evidence that the experience of positive enjoyable interactions can lead to an increase in the motivation of children with ASD to participate in interactions with others. In addition, the results of the study show how positive interactions with their sibling with ASD can increase TD siblings' interest in playing with them (Baker, 2000). This study demonstrates that play between the children can be enhanced by enhancing their environment and without any training of the TD sibling. The study also provides evidence for following the interests of children with ASD and building on their existing motivation.

The limitation of the study is that altering games to incorporate children's perseverative interests such as using video clips and crashing cars could require a lot of work and expertise and may not always be possible. In addition, the baseline and intervention phase of this study were conducted in a clinic away from the distractions and competing interests of the children's natural environment.

Table 1 summarises sibling interventions with siblings of children with ASD.

Table 1

*Interventions that have focused on improving social interactions between siblings*

Study	Participants	Setting and materials	Intervention	Dependent variables	Results
<b>Celiberti &amp; Harris 1993</b>	<b>3 children with ASD</b> All 4 years old <b>3 TD children</b> (7-10 Years old)	Family room With set toys	<b>TD siblings</b> trained to *deliver play related commands *to use social praise as a consequence for appropriate behaviour *to prompt sibling with ASD	<b>TD children</b> *play-related commands * contingent social praise *prompts to ASD child <b>Children with ASD</b> correct responses <b>Social validity</b> –	Increased play interactions <b>TD children</b> expressed increased comfort in interactions and decreased frustration with their sibling with ASD's behaviour Post-training all three ASD children's play appeared more typical.

Table 1 (continued)

*Interventions that have focused on improving social interactions between siblings*

Study	Participants	Setting and materials	Intervention	Dependent variables	Results
<b>Celiberti 1993</b>	<b>9 children With ASD</b>  <b>9 TD children</b> ( avg 7 years 9 months)	<b>Parents</b> provide daily half hour training sessions to TD children  Three groups Manual + professional input Manual + minimum professional input Manual	<b>Parents trained TD siblings to</b> Deliver play related commands Use social praise as a consequence for appropriate behaviour Prompt sibling with ASD (21 specific skills) Manual based	<b>TD children</b> Play-related commands Contingent social praise Prompts to ASD child (21 specific skills) <b>Children with ASD</b> Spontaneous play Spontaneous play related language <b>Social Validity</b>	<b>TD children</b> used many of the behaviours. A relationship was found between the parents acquisition of skills and the TD child's acquisition of skills Anecdotal information from parents of increases in sibling interactions All parent training conditions were equally successful Positive family ratings of social validity

Table 1 (continued)

*Interventions that have focused on improving social interactions between siblings*

Study	Participants	Setting and materials	Intervention	Dependent variables	Results
<b>Strain &amp; Danko, 1995</b>	<b>3 children with ASD</b> ( 3- 4 years old)  <b>3 TD children</b> (3-5 years old)	Quiet room at children's home  3 alternating sets of toys	Modified class room based social skills intervention  <b>Parents</b> trained to train the <b>TD children</b> to :  Initiate play  Maintain play  Praise sibling	<b>Parent prompts</b>  <b>Child with ASD</b>  Initiations  Responses  <b>Social validity.</b>	<b>Parent's</b> prompts of their children increased  <b>Parental</b> praise was relatively low  <b>Children with ASD's</b> positive interactions increased.  <b>Social Validity.</b>  All parents enjoyed the study, most reported that the study was useful .



Table 1 (continued)

*Interventions that have focused on improving social interactions between siblings*

Study	Participants	Setting and materials	Intervention	Dependent variables	Results
<b>Baker , 2000</b>	<b>3 children with ASD</b> (5 – 6 years old) <b>3 TD children</b> (7- 8 years old)	Playroom at the university <b>Generalisation probes</b> playroom at home Children's school A number of games	Both siblings taught to play a modified game that incorporated the sibling with ASD's perseverative interests.  Children allowed to play with a selection of toys including the modified game	<b>Child with ASD</b> % of intervals engaged in social play % of perseverative behaviour attention behaviour affect <b>TD child's</b> affect <b>Social Validity</b>	<b>Child with ASD</b> All increased their social play in all conditions after the introduction of the game  All increased their joint attention behaviours % of perseverative behaviour declined All the siblings affect became more positive after introduction of the game All the TD children seemed more positive about their sibling with ASD in their post-intervention interview.

Table 1 (continued)

*Interventions that have focused on improving social interactions between siblings*

Study	Participants	Setting and materials	Intervention	Dependent variables	Results
<b>Tsao &amp; Odom 2006</b>	<b>4 children with ASD</b> (3-6 years old) <b>4 TD children</b> (4-11 years old)	Family room children's home With selected toys	Modified peer intervention programme. <b>TD children</b> took part in teaching sessions where they were given information on target skills and feedback, Adult verbal prompts	<b>Child with ASD</b> Attention behaviour (including joint attention behaviour) Social initiation, Social response <b>TD child's</b> Social initiation, Social response <b>Social validity</b>	<b>Children with ASD</b> Modest increases in positive social interactions Strong positive increase in responsive joint attention <b>TD children</b> 3/4 children increased social initiations to <b>siblings with ASD</b> <b>Generalisation Probes</b> TD children's behaviour generalised but <b>Children with ASD</b> 's behaviour did not. <b>Social Validity</b> Improvements in 3/4 children

Table 1 (continued)

*Interventions that have focused on improving social interactions between siblings*

Study	Participants	Setting and materials	Intervention	Dependent variables	Results
Stewart, Carr & Le Blanc 2007	1 child with ASD 10 years old 1 TD child 10 years old (The children are fraternal triplets)	Family home	The children's mother and the TD child were instructed in how to together deliver behavioural social training with the child with ASD. They learnt to instruct, model, rehearse, and give feedback to the child with ASD.	The mother and TD child's joint delivery of the BSD model deliver instructions, modelling and rehearsal and feedback. <b>Child with ASD</b> use of appropriate conversational skills eg eye contact, awareness of other's interest. <b>Social validity.</b> Parent rating of the acceptability and usefulness of the treatment	<b>Child with ASD</b> increased his use of appropriate conversational skills The mother and TD sister correctly delivered the model for most of the trials with above 80% correct. <b>TD sister</b> learnt to prompt appropriate conversational behaviour Parent reported that the treatment was useful and acceptable.

## Summary

Although, most of the studies reported some maintenance data, the data was only on short-term maintenance therefore the long-term maintenance of the studies is not known. In addition, the very small number of children involved in the studies makes it difficult to draw firm conclusions. These studies provide evidence that TD children can learn and use new strategies to use with siblings with difficulties. Two interventions documented that increases in enjoyment in siblings' interactions paralleled increases in the sibling with ASD's joint attention skills (Baker, 2000; Tsao & Odom, 2007). This is consistent with the results of Siller & Sigman's (2002 & 2008) longitudinal work that joint attention skills develop as a consequence of the quality of the interactions between children and those close to them. The finding that sibling interventions have resulted in increases in children with ASD's joint attention provides evidence that sibling interventions can enhance the development of the child with ASD.

Research on promoting interactions with children with ASD suggest that following their play and using responsive non-directive strategies promotes interaction between a child with ASD and others (e.g. Siller & Sigman, 2002, 2008; Wimpory, et al., 2007). In addition, the use of directive strategies requires the child with ASD's play partner to adopt a teaching role while the use of responsive non-directive strategies may encourage more equal roles (Trent et al., 2005). The use of non-directive responsive strategies are likely to be closer to the strategies TD children naturally use with their siblings with ASD (Knott et al., 2007).

However, in the sibling interventions for children with ASD where the TD children were taught skills, the children were mainly taught directive strategies such as ways to prompt the children with ASD and ways to organise their play (e.g. Celeberti, 1993; Celeberti & Harris, 1993; Strain & Danko, 1995; Tsao & Odom, 2006). Research also suggests that interventions are more likely to generalise and maintain if they are situated in the child's

natural environment (Rogers, 2000). All of the interventions, excluding a small number of generalisation probes, took place in a designated room or in a clinic.

None of the studies discussed the influence of the intervention on other siblings in the family. It seems that the success that most studies had in getting TD children to use new strategies was partially due to the efforts of the parents involved in the studies (eg. Celiberti 1993; Stewart et al., 2007; Strain & Danko, 1995; Tsao & Odom, 2006). Baker's (2000) intervention differed from the other interventions in its indirect facilitative approach with the involved adults primary role being was to set up an environment that encouraged and motivated the children to interact.

There was little mention in the studies of providing the TD children with any information on their siblings' strengths and difficulties. Despite this, it is likely that the TD children did increase this knowledge incidentally through their involvement in the studies. Tsao & Odom (2006) in their study prepared the TD children for possible rejection by their siblings with ASD and encouraged the children to persist in their actions. The TD children in their study were able to maintain their behaviours towards their siblings in a generalisation probe when their siblings were not being responsive. Their maintenance of their behaviours suggests that Tsao & Odom (2006) succeeded in helping the TD children be persistent. In Celiberti & Harris' (2003) study, the TD siblings' intention was drawn to the responsiveness of their siblings with ASD.

All of the sibling studies that reported the TD siblings' feelings about being involved, reported that the TD siblings enjoyed being involved (eg. Baker, 2000; Celiberti, 1994; Strain & Danko, 1995; Trent et al., 2005; Trent- Stainbridge et al., 2007). All of the studies reported positive results. One consequence of all the studies was that the TD siblings received extra adult attention. Many of the studies reported that the children's parents were involved in

prompting their children's behaviour. One of the active ingredients of the studies might have been increased adult attention, including increased parental attention, for the TD siblings.

The success of Baker's study, which did not involve the TD siblings learning new skills, suggests that the common active ingredient of the studies may have been an increase in the enjoyment of the siblings in interacting together. These findings suggest that involving TD children in interventions with their siblings with ASD can result in positive outcomes for both children. In addition, these findings suggest that successful sibling interventions promote the enjoyment of both children and help the TD child develop positive expectations of their ability to interact with their sibling with ASD.

None of the studies discussed ethical concerns about involving TD children in interventions where the primary purpose was to enhance their siblings' development. The cost and benefits of being involved in the project for the TD children were not examined.

## **Conclusion**

The research reviewed here suggests that children with ASD need typical interactions and play with their peers. Siblings, like peers, are able to provide children with ASD with typical play experiences. Using siblings in interventions avoids some of the problems of using unrelated peers with whom the child with ASD is unlikely to have a long-term relationship. Findings show that parents' mental health is also an important influence on sibling relationships as healthy family functioning supports healthy sibling relationships (Orsmond & Seltzer, 2007). There is evidence that suggests that providing the TD siblings of children with ASD with appropriate information about their sibling's difficulties and support to cope with the stresses that having a sibling with ASD can bring may enhance the sibling relationship and promote the well-being of the TD child (Rivers & Stoneman, 2008).

The research findings on previous interventions suggest that interventions that enhance both siblings' enjoyment in their interactions, and those that enhance the TD child's attitude and expectations of their sibling with ASD best promote the development of the child with ASD. These findings also suggest that indirect approaches, where the child with ASD's play is followed to build on their existing motivation and that are embedded in the natural environment, could potentially enhance the sibling relationship and the well-being of both children.

The results of previous sibling interventions suggest that the active ingredients in these interventions that have enhanced the interactions between the siblings have been increases in both children's enjoyment in interacting together, improvements in the TD children's expectancies of their siblings, adult support, and encouragement of their interactions. In addition, research suggests that warm close relationships, facilitative behaviour by adults, responsive strategies that are compatible with the natural style of the children, the opportunity to engage in mutually enjoyable games and the use of the natural environment could also be active ingredients in interventions to promote interactions between siblings when one sibling has ASD.

Research on the TD siblings suggest information on their siblings' strengths and difficulties, emotion knowledge and the opportunity to have enjoyable experiences with their sibling with ASD might enhance their well-being and provide benefits to outweigh the cost of being involved in a sibling intervention.

## **Rationale for the Original Study**

The intention of this study was to take some of the findings described in the literature review and put in place a sibling-intervention strategy. Key findings in the literature review established that i) interventions with siblings can be efficacious; ii) sibling interventions share

the advantages of peer interventions, yet do not share many of their limitations; and iii) that the results of recent research suggest ways that sibling interventions could be changed which might result in them being more effective.

This study ultimately differed from that originally proposed. Here I describe the original study. The subsequent changes, and the reasons for them, are described in the methodology section

This study aimed to add to existing research by teaching the TD sibling to use non-directive responsive strategies with the children with ASD. To date, most sibling interventions have taught the TD siblings how to use predominantly directive strategies with their siblings with ASD. For example some sibling interventions taught TD children how to prompt and reinforce their siblings with ASD interactive behaviour (e.g. Celeberti & Harris 1993; Strain & Danko, 1995) and some sibling interventions taught TD children to organise social interactions with their siblings with ASD and provide feedback to their siblings (Tsao & Odom, 2006; Stewart et al., 2007).

The decision to teach responsive behaviours to the TD siblings was based on research findings: i) that the use of responsive strategies with children with ASD increases their social engagement thereby promoting their social and communication development (Kim & Mahoney, 2003; Siller & Sigman, 2002 & 2008); ii) that the use of undemanding responsive strategies, such as commenting, were more likely to elicit social interaction with a child with ASD than directive behaviours, such as asking questions (Goldstein & Kaczmarek, Pennington & Shafer 1992; Siller & Sigman, 2002 & 2008 ); iii) That TD children can learn to use responsive strategies (Trent et al., 2005; Trent- Stainbrook, et al., 2007); iv) that responsive interventions aim to enhance existing relationships (Wetherby & Woods, 2008) and v) that responsive strategies are similar to the type of strategies TD children naturally use in their interactions with their siblings with ASD ( Knott, et al., 2007).



The goal of all interventions for children with ASD should be to change children's lives in their natural settings (MOHE, 2008). The original plan for this research was that it would be conducted in the child's home and follow child-initiated play as much as possible. This draws upon research findings that interventions based in natural settings and contexts are more likely to result in changes in the children's lives, as the children do not have to transfer learning from one setting to another (Rogers, 2000). Embedding the intervention in the children's natural environment allows the existing skills and interests of the children to be built on (Wetherby & Woods, 2008). Previous interventions have been situated at clinics or in designated rooms in the children's homes (eg. Baker, 2000; Celiberti & Harris, 1993; Strain & Danko, 1995; Tsao & Odom, 2006).

As well as teaching the TD children responsive strategies, the original plan was to: i) give the TD children information about their siblings with ASD to help them understand their sibling's strengths and difficulties better; ii) to give the TD siblings information on emotions and iii) to introduce the children to games and activities that incorporated both siblings' interests. These additional components drew upon research that suggested such aspects would increase the warmth and closeness between the siblings (Baker, 2000; Campbell, 2006; Kennedy & Kramner, 2008; Rivers & Strongman, 2008).

It was assumed, on the basis of previous research, that it would be the TD siblings' use of strategies that would mediate any improvements in the children's play interactions (Girolametto et al., 2007; Trent et al., 2005; Wetherby & Woods, 2008). The other components of the intervention were included to help motivate the TD siblings to use the responsive strategies. It was assumed that increasing the warmth and closeness between the siblings would benefit both siblings.

In this study, three interrelated research questions were to be investigated. The first: would the TD sibling's participation in the proposed training programme result in their increased use of responsive strategies with their sibling with ASD?

The second question: would the increased use of responsive strategies by the TD child result in an increase in shared attention between the siblings during play?

The final question: would an increase in shared attention between the siblings result in increased levels of happiness for both children when they play meaning that both children enjoy playing with each other more and are more motivated to play with each other?

## Chapter 3. Methodology Section

### Methodology

#### Design

The final design differed markedly from the design that I originally intended to use. My original design was inspired by the studies (reviewed above) which indicate that training peers, parents and siblings of children with ASD had produced quantifiable changes in the behaviour of children with both ASD, and with other developmental difficulties (i.e. Bass & Mulick, 2007; Grolmeto et al., 2007, Tsao & Odom, 2005; Trent et al., 2005). I originally intended that the project would produce quantitative data.

The data were to be collected utilising a multiple-baseline-within-participants-design. There were to be three major groups of dependent variables i) the use of responsive strategies by the TD children (Trent, et al., 2005); ii) the attention behaviours of the child with ASD (Lewy & Dawson, 1992; Pierce & Schreibman, 1995; Baker, 2000) iii) changes in the affect of both children (Baker, 2000; Koegel, et al., 2005). These measures were to be made using video footage of the two children taken after the intervention session. The variables were all defined so that the number of 10-second intervals in which a variable from the group was observed within a 10-minute period would be recorded as a percentage.

The ultimate purpose of the project, like previous sibling interventions, peer interventions, and parent-mediated interventions, was to primarily enhance the development of the child with ASD. The TD sibling's role was to be that of a change agent (eg. Baker, 2000; Celiberti & Harris, 1993; Strain & Danko, 1995; Tsao & Odom, 2006). It was assumed, in addition, that being the change agent would bring benefits to the TD sibling. The measures were designed so that tentative conclusions could be drawn about the efficacy of the project in training the TD siblings to use responsive strategies and the influence of the TD

siblings' use of responsive strategies on the social engagement of the children with ASD.

Other sibling interventions have addressed similar questions about strategies and their influence (eg. Tsao & Odom, 2006).

### **Unexpected responses to the project**

The intervention was built on a number of assumptions. The measures used in the project were based on these assumptions: i) that the proposed design met the needs of the families involved; ii) that the proposed design benefited both siblings; (iii) that the siblings' interactions would be better quality if the TD sibling was taught responsive interaction strategies; iv) That increases in the children's social play would be facilitated by the TD children's use of responsive strategies; and v) that the variables involved could be controlled well enough so that the measures used would measure what they were meant to measure.

#### **Assumption 1. That the proposed design met the needs of the families.**

The initial meeting with parents and children suggested that there was some discrepancy between the parents' and children's hopes for the program and the program's design and aims. When I explained the project to the children's parents in the first interview, it became apparent that one of the attractions of the project for several of them was that it would give their TD children attention and an opportunity to discuss their feelings about their sibling with ASD. They were also interested in the project because they were keen for their children to play well together. I had expected that they would be primarily interested in the project because it could help their child with ASD's social skills. On reflection, however, the parents' attitude was understandable. They cared about the needs of both their children and the children with ASD were all already receiving help for their difficulties. In my initial conversation with the TD siblings, they seemed to like the idea of playing with their sibling with ASD being more enjoyable and were happy to be the focus of the intervention.

**Assumption 2. That the proposed design benefited both children.**

“The typically developing children will be coached in strategies that previous research has demonstrated facilitates interactions between others and children with ASD .....

Although these strategies all emphasis the needs and wants of the child with ASD, research shows that when other children join children with ASD in their play, the children with ASD eventually learn to participate in a broader range of reciprocal games that are more likely to satisfy the wants of both children (e.g. Baker, 2000)” (Neame, Human Ethics Form, 2008, p. 3).

I had assumed that both children would benefit from the intervention. This assumption appears to be inherent in most sibling interventions (eg. Celeberti 1993; Celeberti & Harris, 1993; Tsao & Odom, 2006). The first session I conducted highlighted that my initial assumptions may not have been correct and that there were some risks to the intervention.

In one family, although the TD girl cooperated initially she seemed keen to find reasons why my suggestions would not work. For example when I suggested that she make a comment about her brother going down the slide, she said she could not do that because the neighbours would hear. After our session, she went outside to play with her brother.

Unfortunately, by then he had decided that he wanted to play with me not his sister. So in this case my intervention decreased engagement between this sibling dyad. In addition, the TD child’s response was to say that she did not want to play with her brother so it seemed that my intervention resulted in a decline in the TD child’s motivation to play with her brother.

The response of the TD child to the initial session and the subsequent unfortunate consequences of my trying to encourage play between her and her brother with ASD, I suggest that my initial assumptions that both siblings would benefit may not have been correct. This led to me to consider the intervention from the perspective of the TD children.

Their perspective was not addressed in the original design. Given the time and energy TD children invest in sibling interventions it has been suggested that there is a need to assess the benefits for the TD children in sibling interventions (Trent et al, 2005). Consequently, I decided that being mindful of the needs of the TD children necessitated being flexible within the intervention. For example, I had originally intended to discuss children with ASD's difficulties in understanding emotions in the emotion knowledge session. However, as the TD child enjoyed the book and the game so much I decided not to risk diluting their enjoyment with a discussion about ASD. This flexibility, of course, compromised the integrity of the original experimental design.

**Assumption 3. That measuring the quantity of changes provided useful information.**

I had initially assumed that change in the quantity of the children's social behaviours and interactions would reflect change in both children's enjoyment in playing together. Increased social behaviours and interactions between siblings during play sessions have been used in previous studies as an outcome measure of success (eg. Baker, 2000; Tsao & Odom, 2006). Increases in the quantity of interactions may not be a valid measure of increases in quality of the children's interactions (DiSalvo & Oswald, 2002; Owen-DeSchriver, Carr, Cale & Blakely-Smith, 2008). "Reliance on quantitative measures ignores the fact that often the interactions of children with autism remain idiosyncratic" (DiSalvo & Oswald 2002,p.2004).

Tsao & Odom (2006) found in their sibling intervention that the overall amount of time one of the TD girls spent interacting with her brother with ASD decreased throughout the intervention, resulting in negative outcome measurements. However, Tsao & Odom (2006) observed the TD girl improved in her use of social strategies with her brother with ASD during the intervention and there was a concurrent improvement in the social behaviour of her brother with ASD. It seems that even though the quantity of social engagement

between the two children decreased, the quality of their social engagement increased. This finding also provides evidence for the importance of the time spent in social engagement to be quality time.

All the parents valued increasing the quality of their children's relationship. However, not all the parents or all the TD children thought that increasing the quantity of interactions between the siblings was important. I had assumed that increased interactions between the siblings would be an important outcome for both siblings and their parents.

Keen, Rodger, Doussain & Braithwaite (2007), in a study on the influence of teaching parents responsive parenting skills, failed to find significant quantitative changes in social engagement between the child and their parents. Based on quantitative measurements their project could be judged to be ineffective. However, the parents reported significant changes in their child's behaviour. In spite of the results of the quantitative measures, the parents found the project worthwhile (Keen et al., 2007). It seems that measurements of changes in the quantity of interactions provide ambiguous information.

**Assumption 4. That the siblings' interactions would be better quality if the TD sibling was taught responsive interaction strategies.**

The project was based on the hypothesis that teaching the TD siblings responsive strategies would result in their use of responsive strategies which would enhance their social interactions with their siblings with ASD, resulting in the enhancement of the sibling with ASD social skills. This hypothesis was based on the assumption that the TD siblings did not have adequate responsive strategies and that if they learnt responsive strategies they would use them with their sibling with ASD.

I observed during the original baseline sessions all the TD children at some time using facilitative skills and responsive strategies with their siblings with ASD. However, I also observed that they did not use these skills and strategies with their sibling with ASD

frequently. This suggested the possibility that the TD children have the skills and strategies to interact with their sibling with ASD but do not use them due to other variables. For example the TD girl in the first session was not confident in her ability to interact with her brother with ASD and her resistance to my strategy suggestions suggested that her immediate need was support to feel confident and happy about interacting with her brother with ASD, rather than to be taught strategies

An associated assumption was that once the TD children learnt to use responsive strategies they would be motivated to continue using them by the responses of their siblings with ASD. Given that the assumption that TD children did not have adequate responsive interaction skills seemed to be mistaken, the assumption that the responses of the children with ASD would help maintain the TD children's use of responsive strategies could also be mistaken. Assessing whether TD children's responsive behaviour was reinforced and motivated by the behaviour of the children with ASD would have been difficult with the original measurement system, as their behaviour on the video could be motivated by many things, such as being filmed and their parents' and my expectations.

**Assumption 5. I could control the environment so that the measures measured what they said they would measure.**

The original intention was to introduce the intervention into the families' natural environment, using the multiple-baseline approach to control for external variables. This fitted with the scientific practitioner model that I have been trained in and seemed appropriate, in the first instance, to my goal, which was to apply and evaluate these techniques in the families' natural environments. The lack of a contrived experimental environment was important for my project, because my ultimate aim was to establish techniques which parents could apply themselves, at home.



Once I began the project, I found that people's lives and environments are more complex than this experimental model allowed for. During this period it was apparent that there were many different variables that influenced the siblings' behaviour. Strain and Schwartz (2001), writing about interventions in people's natural environments, stated that "in these settings multiple factors, some of which are temporally concurrent and others of which may have occurred hours before, influence the social behaviour of children and adults" (p. 126). The multiple variables could not all be controlled for. In addition, locating the project within an existing relationship meant that there were established patterns of interaction between the children that further influenced their responses to the intervention variables.

The children's behaviour was influenced by experiences earlier in the day. For example on one occasion I arrived at the family's home to find that the boy with ASD was refusing to come out of his room and refusing to let anyone in his room. They were influenced by concurrent events such as whether the weather was warm and dry enough for outdoor play. The children's attitude towards their sibling was influenced by prior events with their sibling. On one visit to a family, the TD child was upset with her brother with ASD, as he had inadvertently killed her pet gold fish.

The weather was an important uncontrollable variable. The project started in late summer and went into winter. Three of the sibling dyads interacted more frequently on outside play equipment than they did inside. Even if the intervention managed to increase these children's play behaviour indoors, comparing data during the baseline phase, and the intervention phase, as the weather became colder, would have resulted in an apparent negative effect across the intervention.

There was also evidence that my presence during the baseline phase was influencing the children's behaviour. During the project, the TD children were encouraged to be near

their sibling with ASD to allow for interactions and so they could be filmed in the same space. They were told to play together “as they usually would”. However, at three of the children’s homes, the children were never playing together when I arrived but they would, often with encouragement from their parents, start playing together when I started filming them.

One day, during baseline, one of the children said to me that she did not want to be filmed playing with her brother with ASD for a while. She said that she still wanted to be involved in the project but that she did not want me to film her playing with her brother every time. Further discussion revealed that she felt pressure to interact with her brother and felt failure when he would not play, when I was filming. During my previous visit, she had been rejected by her brother and had felt embarrassed about her failure to engage him in play.

Illness in the children and general tiredness was a significant influence on the children’s behaviour. During the project, three mothers reported health concerns, which were difficult to detect in their child with ASD. The ill health of the children is likely to have influenced their interaction with their TD siblings. Life events also may have influenced the children’s behaviour. These included bereavement of a friend and the arrival of a foreign home-stay student. Such events cannot be controlled for (Owen De-Schryver et al., 2008; Strain & Schwartz, 2001).

There were professionals involved in the children’s lives, who also may have influenced the development of the siblings’ social interactions. The professionals and the children’s families were all, during the time of the project, continuing to actively trying to help the child with ASD’s social skills development.

The above causes influenced my ability to carry out the study as designed. All of the above variables influence the impact of an intervention, even if well-controlled, on children’s behaviour (Anderson et al., 2006; Orsmond & Seltzer, 2007). Even research that has reported

overall positive results has found variable results between their participants (Owen De-Schryver et al., 2008; Trent, et al., 2005; Trent-Stainbridge, et al. 2007; Tsao & Odom, 2006). These mixed results from research on interventions with children with ASD provide evidence for the influence of variables on the children's behaviour that have not been able to be identified and measured in the research (Orsmond & Seltzer, 2007; Worley & Garfinkel, 2002).

### **Difficulties in comparing the outcome of the project across the participants**

The differences between the TD children in the project resulted in the intervention programme being changed to suit their likes and dislikes. Situating the intervention in the children's natural environment also meant that the intervention programme was altered due to family input and needs. For example, I was keen to build on two sibling's play on the trampoline with a game using identical balls. However, their father felt that the children's pattern of playing rough and tumble games on the trampoline was too strong to alter so an alternative game was organised. Working with the parents in their own home results in a more collaborative approach and a more individualised approach.

The responses of the children with ASD in the current study to their TD siblings varied considerably. Characteristics of the child with ASD such as their language ability and their joint attention are likely to influence their responsiveness to interventions (Anderson et al, 2007; Sherer & Schreibman, 2005). There was considerable variation among the children in the current project's language ability and joint attention.

### **Changes in the Project**

My initial observations during the baseline period of the project and my initial experiences in the intervention period of the project caused me to reassess the assumptions

underlying the project. I realised that the assessment of the intervention needed to be guided by consideration of these assumptions. My initial experiences suggested that I needed to be mindful of the needs of the TD children, as well as the needs of their siblings with ASD, as I undertook the intervention section of the project and be able to adapt the intervention section when needed. My initial experiences also suggested that to understand the outcomes of the current project, especially on the TD children, I needed to be able to capture their subjective experiences of being involved in the project.

### **Accounting for the unexpected findings**

I decided to move to a qualitative research methodology so that the richness of the children's lives in their natural environment could be captured and the interaction between the intervention, the children, and their environment could be analysed and interpreted. Qualitative research acknowledges the subjective nature of knowledge and the importance of situating research in the natural context to capture a better understanding of the data (Patton, 2002). The qualitative approach allows research to reflect on findings that occur during the project that had not been anticipated and allows subtle findings to be examined. The qualitative approach allows assumptions to be explored and examined. The filmed material, the discussions, and interviews with the children and their parents would provide rich resource material for insight into the realities of the children and their families' lives.

There has to date been only a small number of studies on enhancing sibling play in their natural environment. Qualitative methodologies are particularly useful in areas that little is known about (Gay & Airasian, 2003 in Barr, McLeod & Daniel, 2008). An advantage of using qualitative research in the current project is that it allows the process of the project to be explored (Nelson & Damco, 2006). The original measuring system of the project would have produced information on changes in the quantity of the TD children's use of responsive

strategies. A qualitative methodology allows information on what factors influenced the TD children's use of responsive strategies to be produced.

The project aimed to improve the lives of both siblings. Improving someone's life means improving that person's experience of their life. Likewise improving the quality of a relationship means improving the experience of the relationship for those involved. The experience of phenomena is a subjective state. Qualitative methodology provides methods for discovering and exploring people's subjective experiences (Parker, 2004). The use of qualitative methodology in this project allowed the exploration of how the project affected the TD child's subjective experience.

A qualitative approach allows the researcher to make use of the knowledge and understanding they gained from being actively involved in the project. I delivered the intervention component of the project and so was actively involved with the children and their families. If I had continued with the original plan for assessment of the project, I would have had to take an objective role, which as an active participant would have been difficult. In addition, my involvement in the children's lives meant that I participated in discussions with the children and their parents, which offered me insights into their subjective experience of the project. Using a qualitative approach allowed me to use the rich data from the project to start making sense of the complex interaction between the project and the children (Taylor & Bogdan, 1998).

Qualitative methodology is useful in complex situations, such as projects set in the natural environment, as it enables the interactions between complex phenomena to be captured (Nelson & Damico, 2006). The original quantitative approach would have produced data that were compromised because the complex effects of the context of the project and the existing relationship of the siblings would not have been able to be fully accounted for. The use of qualitative studies in children's natural environments has enabled researchers to

uncover significant new findings in other areas. One example is Evans' (1998) study on deaf children in their natural environment, which uncovered features of the children's environment that contributed to their language development.

### **The qualitative framework used in this project**

The qualitative approach used in this project is best described as reality-oriented qualitative inquiry (Patton, 2002). The aim of a reality-oriented qualitative inquiry, is to find explanations for the ways phenomena act and interact, and is similar to the aims of quantitative methods (Patton, 2002). In reality-oriented research the trustworthiness and credibility of the data and the rigour of the research is important. In addition, whilst true objectivity cannot be achieved in reality-oriented qualitative inquiry, steps to reduce and clarify the influence of subjective biases on the findings are taken (Patton, 2002).

### **Making the process rigorous**

A variety of sources of data were used to enhance the credibility of the data. There were videoed interactions between the children and on some occasions of the children, and their parents, working with myself. Originally, the plan was to video the children playing together once the TD child and I had an initial discussion. Sometimes the only interaction between the children would be during the training session with the TD child. To capture any interactions that occurred between the children, I often filmed during my meeting with the TD child.

I took notes after my visits with the family and began a journal once I changed the method from quantitative to qualitative. Once I changed the methodology, I became aware of the need to keep more literal notes on my meetings with the families. I also had an interview with a parent, or both parents before the project began as well as a meeting with the TD child. During the intervention period I had regular discussions with the parents, and once the intervention was finished I had a semi structured interview with the parent(s).

To limit the bias of my observations I questioned the assumptions I used in interpreting the observations. During the intervention phase, I reflected on my behaviour and my observations and as part of the final analysis, I reviewed my data including the journal and reflected on my reflections. In the final interview with the parents and the final informal discussion with the children, I solicited their views on the project and when I analysed the findings, their comments and my reflections were compared to theirs, to discover areas of convergence and difference.

This process of reflecting led to some interesting discoveries about my process in the research. On one occasion, a TD brother asked how long he had been playing with his sibling with ASD. I assumed that he viewed playing with his brother as a chore. On revisiting the information, I can also see that it is equally likely that the TD brother asked how long he had succeeded in playing with his brother with ASD because he was proud of being able to play successfully with him for such a length of time. This led me to realise that I had been originally very sensitive to data which cast doubt on the assumption that involvement in the project would benefit the TD sibling.

### **The use of relevant literature**

Another way of enhancing the research is the use of existing relevant literature. Existing literature on the topics of interest in this research is presented in the literature review and throughout the research. Existing literature provides a context in which to identify consistencies between previous literature's findings and current findings. Existing literature also provides a context in which to identify and explore differences between the current findings and existing literature. Relevant literature was identified and consulted.

## **Conclusion**

The reality of implementing the proposed sibling intervention resulted in my questioning the assumptions that the sibling intervention had been based on. A qualitative research design allowed the examination of the assumptions and enabled the intervention to be changed to accommodate new findings during its implementation.

## **Method**

### **Participants**

Four sibling dyads and their families were the focus of this project. All the children with ASD were boys and they were all younger than their TD siblings. One family responded to an appeal in the newsletter of the New Zealand Autistic Society newsletter and Group Special Education referred the other three families to the project. All participant names have been changed to protect their privacy.

### **Chloe and Samuel**

Chloe was a six-year-old girl who liked horses, reading, making up imaginary games with her soft toys, and playing with trains and construction type toys. Samuel was a four-year-old boy who loved Thomas the Tank engine, horses, and rough and tumble games with Chloe or as Chloe called them “tag and tumble games”. Samuel’s language was delayed. He had some words and would make two to three word sentences.

They lived with their parents Deb and Richard and their three-year-old sister Lily. Both Deb and Richard worked part-time. The hours they worked varied from week to week and the children all had busy schedules between school, preschool and kindergarten and other activities. Two ABA trained therapists had weekly sessions at home with Samuel. Their home life was tightly scheduled and busy.



Deb described Chloe as “motherly and sensitive “and said that Sam had a well developed sense of humour. Deb told me that she had attempted a conversation with Chloe about Samuel’s special needs but Chloe had seemed uninterested. Chloe had not been told that Samuel had been diagnosed with ASD. Her parents did not want the word autism or ASD used with reference to Samuel. Her mother said she wanted Chloe to think of Samuel just as “Samuel” not as “Samuel who has ASD”.

Their parents reported that Samuel and Chloe did spend time playing. Their play consisted almost entirely of rough and tumble play. Both parents and Chloe reported that Chloe sometimes got hurt playing with Samuel and would frequently get tired of the rough and tumble play. I also observed Chloe getting hurt and tired whilst playing with Samuel. Both parents said they were keen for Samuel and Chloe to extend their play repertoire.

### **Kathryn and Andrew**

Kathryn was a seven-year-old girl who liked dancing, singing, dolls, pink and Disney movies about Princesses. Kathryn had very firm ideas about what she liked and did not like. She would not look at two of the books I brought because they did not resemble her choices enough.

Andrew was a five-year-old boy. He liked watching certain parts of movies repeatedly, music, and bouncing on the trampoline. Andrew did not have functional speech although he made many sounds. He would follow some instructions and sometimes respond to requests, indicating that he had some receptive language. He communicated through a Picture Exchange Schedule, primarily with his mother. He, like Kathryn, had many toys such as toy cars and trains. His toys were distinctly masculine toys whilst Kathryn’s toys were distinctly feminine.

Both children went to different schools. Andrew had an ABA therapist work with him at home once a week. They lived with their parents Lisa and Mark. Mark worked outside the

home whilst Lisa looked after the children and the home. Lisa said that Andrew is affectionate with her and likes cuddles and that he likes people who are animated and positive. Lisa said that Kathryn is a sensitive girl who, like her brother, enjoys music.

Both Lisa and Kathryn reported that Kathryn and Andrew seldom played together. When they did, it was on the trampoline. Andrew had a bedroom and a study in the house where he spent most of his time. Lisa felt torn between including him in the family and giving him time alone.

### **Gracie and Grant**

Gracie was a six-year-old girl who liked reading, music, dancing and playing games with the whole family. Grant was a four-year-old boy. He read, liked numbers, Thomas the Tank Engine and cards. Grant had a good vocabulary although his speech was flat unvaried and frequently difficult to understand. Gracie and Grant lived during the week with their Mum, Rose, their four older half siblings, Blake, 16, Olivia, 14, Leticia, 12 and Lyndon, 10 and a foreign student in the top half of a large house. Their grandmother and an aunt with Down Syndrome lived in the bottom half of the house. Once a week their father had dinner with them all. At weekends, they lived with their father.

Rose, said that Grant likes to talk a lot and that he has strong visual skills. He will always find the character “Wally” in the game “Where’s Wally”. Rose said that in some ways Grant is easier to parent than a TD child as he does not get upset if he does not win games. Rose said that Grant was easier to leave with a baby sitter than her other children had been because as long as the babysitter followed the right bed time ritual with him he would cooperate. Rose described Gracie as very musical and a kind and placid girl. She likes her older sisters doing her hair. Her older siblings said that Gracie is the real baby of the family, even though she is older than Grant, and they often affectionately called her “bubs”.

In the initial interview, Rose said that Gracie and Grant could play together but they very seldom played together. She also said that the family would like Grant's turn taking behaviour to improve so that he could play more successfully with Gracie and other children and that the family was actively trying to help him with this.

### **Ezra and Ollie**

Ollie was a ten-year-old boy who was keen on soccer, chess, playing on the computer and liked construction toys. Ezra was a five-year-old boy who liked Fireman Sam, Postman Pat, construction toys, and playing on the computer. He was able to communicate through speech although his speech was delayed. He would greet people who came to the house and would always very politely take leave of people when they left the house.

Both Ollie and Ezra went to the same school. Ollie and Ezra lived with their parents, Malcolm and Juanita, and their thirteen-year-old sister Helena. Malcolm and Juanita both work outside the home. They always have a day off during the week home together.

Malcolm and Juanita described Ollie as a serious, sensitive, and caring boy and told me a story about how Ollie had found and cared for one of their friend's sons, a severely autistic child, who had wandered off. Ollie said that Ezra rarely gets angry. Malcolm and Juanita both said that they were lucky with Ezra because he is usually even tempered and relatively cooperative and people generally respond positively to him because of his smiley demeanour.

Ezra and Ollie would play harmoniously with the same construction toys. Ezra seldom acknowledged Ollie's attempts to get his attention, which was frustrating for Ollie. Ollie said in the initial interview, that he wanted Ezra to interact more with him when they played and to be able to play together with the ball outside.

## Setting

The project was conducted in the children's homes and in a departure from previous interventions, the children were not confined to one room of the house (eg. Celiberti & Harris, 1993; Tsao & Odom, 2007). Instead they were allowed to use their home as they normally would. The reasons this site was chosen are 1) This allowed the children to move around their home as they normally would and enabled the researcher to help the children build on their existing, activities and interests.

2) This took cognizance of research that social behaviours are strongly influenced by the environmental context (Strain & Schwartz, 2001).

“Social behaviour cannot be taught in isolation it must be taught in the contexts in which it will be used” (Strain & Schwartz, 2001, p. 127).

## Procedure

The project began with an interview with the children's parent(s) to give them information about the project, to gather information about their family and children, to discuss how they felt the project could potentially help their family and to gain their consent. Once the parents' consent was gained, an interview was conducted with the TD children to explain the project, to discuss what they would like to gain from the project, and to gain their consent.

Once the TD child gave consent there was an observation period of between 3 to 7 weeks. The number of weeks the children were observed varied because it was decided under the original design to use a multiple baseline. During the observation sessions, the children were asked to stay in the same area as their sibling, so they could be filmed together and to play as they normally would. They were filmed for ten-minute periods once a week.

## **Intervention Program**

After the observation period, the intervention period began. The intervention period consisted of seven home visits. These home visits occurred at the same time of day as the observation visits. The intervention visits were longer than the observation visits to allow time for the TD child to have discussions with me, and to allow time for play between the children. The original plan was that I would spend the first half hour talking, reviewing the DVD footage and role-playing with the TD child. I would then film the siblings interacting, without input from me, after we had finished.

In reality, in order to capitalise on all opportunities to encourage interaction between the siblings, the sessions rarely ran to the original plan. For example, when I arrived at one house the ASD child was waiting for me so that he and his TD sister could play Snap with my cards. My presence and the presence of other family members meant that the sibling's interactions often included other people. In addition, it became apparent that it was easier for the TD child to learn a new strategy whilst interacting with their sibling with ASD rather than through discussion and role-plays, as had been planned. To encourage the participation of the ASD child they were also prompted and encouraged in their play with their TD sibling. Changes were made throughout the intervention phase in order to maximise learning, and any positive effects of the intervention.

Three methods were used in the intervention to help the siblings enhance their relationship. The first method was providing the TD children with both descriptive and explanatory information about their sibling with ASD's disability. I gave each of the three girls a scrapbook with a questionnaire about themselves and a questionnaire about their brother to fill in so that they could identify areas of similarity between themselves and their brother and areas of difference. They were adapted from a personality profile in the "The friendship formula" (Schroeder, 2008).

I discussed with the TD children ways they were like their sibling with ASD and ways they were different. Books, pamphlets, a DVD for the siblings of children with ASD, discussions cued by observing the video footage of the children and in response to issues raised by the children were all used to increase the understanding of the TD child of their sibling with ASD. The emotion component consisted of reading “The Blue Day Book for Kids” by Bradley Trevor Greive (2005) together and a game where the TD child and I took turns at pulling emotion faces and guessing the emotion.

The second method was teaching the TD child some strategies to help their interactions with their sibling with ASD. These strategies were indirect child-oriented strategies. For example, following the child’s lead, imitating the child, commentating on the child’s activities, and responding to all communication attempts of the child with ASD. There is a strong research base for the use of these strategies with children with ASD (Hwang & Hughes, 2000; Ingersoll, Dvortcsak, Whalen, & Sikora, 2005; Grolmetto, et al. 2007; Wimpory et al., 2007).

The third method involved providing and encouraging the children to participate in games and activities that were attractive to both children and able to be played by both children. Games and activities were chosen based on the observation data, discussions with the TD children and their parents, and literature on games for children with ASD.

One game used with all the children was “Trains and Fairies”. This game was designed to be attractive to both siblings, to have very clear rules that promoted turn taking behaviour, and to have very clear boundaries for each player. “Trains and Fairies” was based on a game described in the book “Autism and Play” by Beyer and Gammeltoft (2000). Some activities, such as using ribbon sticks with music, were trialed primarily because they met the TD children’s interests, and were simple enough to play with the sibling with ASD.

The methods and resources used varied somewhat between the sibling dyads depending on their responses to the materials and resources and the information I had gathered on their likes and dislikes, strengths and weaknesses. Although the role of the parents in the intervention period was not specified, in each family, a parent or both parents became involved in the project. Some parents participated in discussions whilst some parents actively supported their child with ASD in activities. Most parents at some stage made suggestions and prompts to their children.

After the intervention period was over, I left the families a DVD of the children playing together. I returned a month later and interviewed the parents about their feelings about the project. I also asked the parents to answer some scaling questions about the outcomes of the project for their children. I did not interview the children as I had already discussed their feelings about the project with them in the final sessions. The exception was the 10 year old TD boy who participated in the final interview with both his parents.

## **Identifying Findings**

To identify themes I reviewed all my data sources, and reflected on the data. When I reviewed the data sources, I explored chronologically across all the cases to allow the process of the project to unfold. That is, I read all the initial interviews with the parents at one time to find commonalities and similarities and then read all the initial interviews with the children. I repeated this process a number of times. I reflected on the original assumptions of the project; I made notes on anything that struck me as being significant in the data.

The data were again reviewed to find data that provided evidence for or against the significant patterns identified. I actively looked for material that disconfirmed the findings and suggested alternative findings or limitations to the findings. A finding in the data was

considered significant when a considerable number of pieces of data supported the theme. I then researched literature that was relevant to the findings I had found. This procedure of data analysis and theme generation is in keeping with qualitative research methods (Neuman, 2006).

Finally, in the conclusion I analysed the findings that had emerged as the project unfolded. In the conclusion, I also considered what future research needs to be conducted to confirm or extend the findings from this project so that the findings can provide useful information for the families of children with ASD and the professionals who work with them.



## Chapter 4. Findings

The purpose of this research is to explore and evaluate how the intervention used in this study affected the lives of the children involved. Since this research uses a qualitative method data are presented as descriptive findings, which are organised as clusters around phases of the research. Within the clusters, commonalities, and differences between the children and families were found by repeatedly reviewing the video clips of the children, field notes, interview notes, and journal notes. The findings within the clusters are organised under major headings and sub headings. Descriptions of the findings and specific examples are provided under the sub headings.

For ease of interpretation, specific examples drawn from notes are written in the standard script and examples from the video footage are indented and bolded. Quotes are italicised. Children in the examples are identified only as the TD child or as the child with ASD. However, to preserve the feel of quotes names are used. Relevant research is presented alongside the findings as is the convention in qualitative research (Patton, 2002).

The first cluster presents findings on the pre-existing sibling relationship and the family situation. These findings are from the observation period. The second cluster of findings is from the beginning of the intervention period. This section includes children's responses to being taught strategies to use with their siblings, and the dilemmas and challenges that became apparent in the early part of the intervention period. The third cluster of findings is from the later part of the intervention period. This includes components of the project that proved useful to the siblings and their families. The fourth and final clusters of findings are from final discussions with parents and parent interviews.

## **Cluster 1: Findings from the Observation Period**

### **What the families wanted from the project**

#### ***Support for their TD children***

In the initial interview the parents stressed the importance of their TD children's self worth being enhanced. They all felt that their TD children would benefit from some extra attention and support in their lives.

One mother commented that her TD daughter had low self-esteem, was reluctant to try new things, and was not confident about her ability to interact with her brother with ASD. The mother explained how her son's ASD had meant that her daughter did not experience typical family activities such as socialising with other families and family outings to playgrounds.

The parents' attitudes concur with research findings from parent reports that TD children experience some feelings of neglect due to the extra attention the sibling with ASD receives (Dodd, 2004; Meirrschaut, Roeyers & Warreyn, in press; Phelps, 2009; University of Ulster, School of Psychology, 2007). Bevan-Brown (2004) interviewed the parents and whanau of 19 Maori children with ASD who shared their experiences of raising their children. She reported that some parents felt that attending to their child with ASD meant that they were unable to give their other children as much attention as they would have liked to. She also reported that parents reported making considerable efforts to give their other children opportunities and attention (Bevan-Brown, 2004).

There is research evidence that parents of children with ASD put extra effort into ensuring their other children get as much attention as other children do (Stoneman, 2001). In talking to the parents and the TD children, it was obvious that all the parents made a considerable effort

to ensure that their TD children had the same opportunities as children in families without children with disabilities. All the TD children were involved in after school activities such as dancing, soccer, art classes and horse riding.

***An opportunity for their TD children to discuss their feelings***

Most of the parents thought that their children would benefit from discussing their emotions, especially their feelings about their sibling with ASD. One mother said that although her daughter did not complain, she felt it would be good for her to talk about her feelings. This was because she probably resented the limitations that her brother's disability has put on their lives. Another mother was somewhat concerned that discussing negative emotions could upset her daughter.

***An opportunity for their TD children to increase their understanding of their sibling's disabilities***

Similarly, all the parents thought that giving their TD children information on their sibling's difficulties would be useful. One set of parents made the comment that they hoped that increasing their son's understanding of his brother's disability would help their son cope with his feelings when his brother with ASD's behaviour frustrated him.

Parents expressed their support for including both an emotion component and an information component on ASD in the project, as they felt that would address the needs of their TD children.

***Improvements in the quality of the play between the children***

All of the families were keen to improve the quality of the children's play. The parents of the TD girls reported that their children seldom played together and that the quality of their play together was low. One set of parents reported that when their children played together there was a lot of unhappy shrieking and banging.

The parents of the two brothers involved in the project reported that the quality of their play was generally high and that they played together frequently. The TD brother commented that he sometimes enjoyed playing with his brother with ASD and sometimes he didn't enjoy playing with him.

### **What the TD children wanted from the project**

#### ***The TD children liked the idea of being "special"***

All the TD children were keen to be involved in the project. Their parents reported that they liked the idea of being chosen for the project and the acknowledgement that they had a special role to play. One mother commented that her son liked the idea that it was him, not his older TD sister, who was needed for the project.

It is possible that the project's appeal for some of the children was the prospect of playing new games and the attention of an adult rather than learning new skills to use with their sibling with ASD. In the initial interview, a TD girl asked about the games we would be playing, and one asked about my family. None of the children asked any questions about playing with their sibling with ASD.

### **The relationship between the siblings**

#### ***The TD children had mixed feelings about their sibling with ASD***

The TD children displayed a number of feelings about their siblings with ASD. These were similar to the feelings Bevan-Brown (2004) found in her research. "Siblings were reported to be helpful, protective, embarrassed, annoyed and sometimes "left out" as a result of having a brother or sister with ASD" ( Bevan-Brown 2004, p. xii)."

In the following example, a TD girl is displaying a protective attitude to her brother with ASD. She is explaining what she would say to her friends if they ask her about her brother when he starts school.

***“He’s a bit of a funny boy but you shouldn’t be mean to him. He’s my brother and he’s really really cute, but sometimes he acts really funny.”***

In the next example, a TD girl is being helpful by trying to comfort her brother with ASD.

**The boy starts to cry loudly. His sister dashes around the room going “Where is it?”. She gets a pad and some pens and goes over to him. “Andrew, Andy, drawing, want me to draw something, cats?, want me to draw something, Andrew”.**

In both of these examples, the TD girls are also demonstrating their affection for their sibling with ASD. All the TD children showed, in some way, that they had affection for their sibling with ASD.

Another feeling described by the TD siblings was one of annoyance. In the following example a TD girl describes how her brother’s copying sometimes annoyed her.

**The TD sister is cycling on their deck followed by her brother, on his bike. She says, “Andrew just does whatever I do really. I get quite annoyed sometimes. It’s annoying.”**

Another TD girl’s comment, in the initial interview, indicates that she sometimes felt resentment of her brother. She told me she called her brother “*bruiser*” because he bruised her a lot. She went on to say that she liked him biting her because when he did that she got a great deal of attention from her parents. She then said he scratched her which she did not like and that she really did not like being bitten either. She said that she did not get attention because she was the eldest and that the eldest does not get attention.

### **Play between the siblings**

#### ***The siblings spent limited time playing with each other***

Although I observed play between all the siblings when I videoed them, comments from most of their parents suggested that the siblings did not generally play together. When I

explained to a TD sister that I was going to film her and her brother playing together she said *“But we don’t play together.”*

This is consistent with research that suggests children with ASD make fewer initiations to their siblings than TD children do (Knott, 2007) and that TD children frequently react to the difficulty of playing with a sibling with ASD by reducing their attempts at play with the sibling (Boucher & Wolfberg, 2003; Celliberti & Harris 1993; Doussard- Roosevelt et al., 2003).

In one example playing with a sibling with ASD was observed to be a de-motivating experience. A TD girl went into her brother’s room and asked if she could play the board game with him. He was playing it by himself. He agreed, but then he dominated the game and did not allow a role for his sister in the game. She was in his room for only three minutes.

**The TD girl says “*Grant can we play that game where you roll the dice?*” He says “*No , you’ve got to get the green Henry*” (the green Henry was a card). **He shuffles the cards and says, “*Now I’ve got the red out. You’ve finished*”. She claps her hands and says, “*Yay for Gracie*”. She leans over to get some other games out and he goes, “*Nah, nah, nah, we’re playing this one hold out the purple one*”. He then says, “*Find the pieces, find the pieces*“. Then “*No touch,*” as the TD sister looks through the pieces. When she picks up one of the boards on the floor, her brother says “*Ah, ah, ah, ah*” in a scolding tone. The sister pretends to bang her head on the ground and then she watches her brother. He says “*You’re not playing, get out Gracie, Get out! Get out! Get out!*”****

The outcome of this incident was that the TD girl asked me not to film her with her brother again. Presumably, this was because she did not want to feel obliged to play with her brother again. (Later in the project, she changed her mind and gave me permission to film

them again). When I showed a video from the project to her parents and siblings, she asked me not to show this incident.

***The TD girls' play preferences were different from their brother with ASD's play preferences***

The three girls' toys were generally different from their brother's toys. The games they said they liked to play such as putting on puppet shows were also different from the games their brother with ASD played. In contrast, the two brothers, although there was 5 years difference between their ages, had similar interests such as construction toys and computer games. One of the girls showed me her toys, which were distinctly feminine, and then her brother's distinctly masculine toys. She told me that they never watched each other's DVDs and she did not want to play with his toys. Her mother said that sometimes her brother tried to play with her daughter's toys, but she would get upset. The TD sister said she did not want to play with her brother's toys.

***Play between the siblings increased because they were being filmed***

It seems that the presence of an observer with a camera increased the children's play together. The following conversation with a TD girl illustrates how having a researcher in her home changed her usual routines. Her brother with ASD was riding his bike on their decking and she was riding her bike on the lawn.

***I said, "Do you want to do it where Andrew is Kathryn, then I can see you on the camera as well". She agrees and says, "I could ride my bike and stand up there". I said, "Kay, you just do what you would normally do". She replies, "Yep, I normally go on the slide, but mum and dad won't put it up". She lifts the bike on to the decking and says, "I'm normally inside watching TV."***

The increased play between the children could have been partly due to a perceived expectation to play. It could also have been due to an increase in the TD sibling's motivation to play with their sibling with ASD because of the adult attention.

***Parents prompted and encouraged play between the children***

The parents would prompt and encourage their children to play together, and they would prompt them to pay attention to me. Other researchers have reported that parents prompt play between their TD children and their siblings with ASD (e.g. Tsao & Odom, 2006). At the beginning of the following example, the brother with ASD is in his bed, and his mother encourages his TD sister to go and play with him.

**The girl pulls the sheet from her brother's head. He giggles. The children's mother says, "*Don't wind him up completely, just play*". The boy grabs the girl around the waist she says, "*Yikes, tickly time*". He tries to pull her to the ground. Their mother says, "*You tell him stop*". The girl says, "*Stop*". She escapes and their mother says, "*Are you going to do horsey rides?*" The girl runs to the other side of the room and picks up a large stuffed horse and her brother runs over and jumps on both her and the toy. Their mother says, "*Chloe, why don't you give him a horsey back ride.*" Their mother says, "*Chloe, Chloe!*" and then to me, "*Sorry I probably shouldn't be directing them but we are trying to give them ideas*".**

**The quality of the sibling's play**

***The siblings seemed to enjoy active play together***

When the siblings played games that were active both siblings frequently seemed to enjoy the play. There is research that shows that children with ASD engage in rough and tumble play more frequently than other forms of play, and that they are more likely to engage socially with another person during motor activities (Wimpory et al., 2007).



One pair of siblings frequently played what the TD sister called “*tag and tumble*”. They both seemed to enjoy “*tag and tumble*”. There would be a lot of giggling. I observed all three of the sibling dyads, who had trampolines, playing together on the trampoline. Both the TD siblings and the siblings with ASD seemed to enjoy the activity. Both the mother and the elder sister in one sibling dyad commented that the trampoline was the only place that the siblings played together.

In the following example, the siblings are playing on the trampoline with a ball. They both seem to enjoy the game. The brother with ASD is holding the ball.

**He says, “*Stop, stop, stop, sit*”. His TD sister sits opposite him and watches him.**

**He goes, “*Four, go!*” They both jump to their feet and bounce with the ball**

**bouncing between them. They bounce the ball with their feet. They both laugh as they play.**

The trampoline is a gender-neutral activity and an activity that children of all ages can play. Survey research findings on children between the ages of three and seven with and without developmental delays found that almost all the 166 children in the study enjoyed physical play (Case-Smith & Kuhaneck, 2009). One set of siblings would continue playing on the trampoline as I left their house. This suggests the pleasure of playing on the trampoline maintained their play despite their play being initially prompted by parental prompts and my presence with a camera.

***There were limited interactions between the siblings during non-active play***

Play not based on motor activity between the siblings did not result in social engagement between the siblings. I observed two sets of siblings engaged with play on the same construction toys for between 5 and 10 minutes. Both pairs of siblings played side by side with very little interaction.

As an example, two brothers are sitting on opposite sides of a loop of track, which they are putting together so that motorised cars can drive round the loop. At the time of this example, I had been filming them for two minutes during which the brother with ASD has not looked at, nor spoken to his TD brother. The TD brother attempted to get his attention.

**The TD brother puts a car in the loop and it drives round the loop. He looks at his brother with ASD and says, “Ezra, look, Ezra, look”. He puts his hand next to his brother with ASD and says, “Ezra, look, 1, 2....” The brother with ASD does not respond. The TD brother bends his head down to his brother with ASD’s so he is talking directly into his ear and says “Ezra, look, Ezra!” The brother with ASD does not take any notice.**

The TD brother made another attempt to get his brother with ASD’s attention but his brother did not respond.

The play between the siblings was also very simple, more so than play between TD children. Children with ASD, when compared to matched TD children play in significantly less positive and less complex ways than the TD children (Anderson, et al., 2004).

### **The TD children’s existing skills at interacting with their sibling with ASD**

#### ***All the TD siblings had skills of interacting with their sibling with ASD***

All the TD siblings, at times, used responsive strategies in their interactions with their siblings with ASD. They all spoke in simple sentences and used their sibling’s names when trying to interact with them. In this example, a TD boy was getting the pieces for a train set out of the box and his brother with ASD was watching him.

**The TD brother says, “Ezra, Ezra, look, Ezra!” “Play with the train?”**

The TD siblings were attentive to their siblings and interpreted their sibling's attempts at communication. In the following example, two brothers were working on constructing a road.

**The brother with ASD makes a frustrated noise. The TD brother says, “*Ezra what’s the matter?*” He looks at the pieces the brother with ASD is playing with. The brother with ASD says something like, “*Too bad,*” and then, “*Too hard,*” without looking at his TD brother. The TD brother repeats, “*Too hard?*” and the brother with ASD grunts. The TD brother pushes the pieces together for the brother with ASD.**

In another example, the TD sister interprets her younger brother's actions as an attempt to interact with her, and extends the interaction. They were both bouncing on the trampoline. The younger brother was bouncing behind his sister.

**The boy with ASD falls over his TD sister who stops and faces him. He laughs and punches her (lightly). She catches his hand and pulls him to his feet. He pulls his hand away. She holds out both her hands and says, “*Andrew, Andy*”. She takes his hands and they bounce in a circle while she sings, “*Ring a ring a rosie*”. Then, in time with the words, they both fall down.**

In another example, the TD girl matches her brother's animation levels in their play. They are playing in a bike shed and she has just put one of their toy dogs in a corner.

**The TD girl says, “*He’s in bed,*” and her brother with ASD says, “*Grant’s in bed too*”. She sits down and says, “*Goodnight*”. He yells, “*Wake up!*” She springs up and yells, “*It’s morning,*” and claps her hands. He smiles and yells, “*Wake up!*”.**

In a further example, the TD girl prompts and helps her brother so that he can participate in a game of hide and seek. The TD girl was looking at books and her brother tackled her around her knees. She stepped over him and ran down the hall.

**The brother with ASD starts to chase his TD sister but he sees a toy monkey on the floor, sits down, and starts playing with it. His TD sister calls, “*Samuel, Samuel*”. He ignores her. His TD sister comes back to the doorway and calls, “*Samuel, Samuel*”. Her brother with ASD looks up and starts to chase her. She disappears and he runs down the hall. Then she lets out a little scream and he goes back to the bathroom. She then screams again, he looks behind the door, and finds her.**

All three girls occasionally provided a commentary to their game with their brothers. Commentary on their actions seemed to give a game some structure and make it more interesting for the girls.

### **The TD children’s understanding of their sibling with ASD’s difficulties**

*The parents had only had limited discussions with their TD children about their sibling with ASD’s difficulties*

All the parents of the children reported that they were keen to increase their TD child’s understanding of their sibling with ASD’s difficulties yet they had not discussed the topic fully with them. Parents reported that their TD children did not seem curious about their sibling’s disabilities.

One of the mothers described how she had tried to talk to her TD girl about her brother’s special needs and her daughter had barely acknowledged her questions and started talking about something else. One set of parents reported that although their son asked questions about lots of things he had only once asked about his brother’s special needs. On that occasion, he asked if his brother was like a boy at his school who had a disability. One mother said that she had intended to talk about her son’s difficulties with her TD daughter earlier but she had not found the right time.

***The TD children did not seem to have an understanding of their sibling's difficulties***

The TD children did not seem to have an age appropriate understanding of their sibling's difficulties. All of the children mentioned that their siblings had difficulties with speech. One girl said that her brother was not fun to play with because he had "autism". She indicated that "autism" meant that he was "bossy" and therefore not fun to play with. I observed some TD siblings, of children involved in the project, struggling to explain to a foreign student why their brother with ASD was behaving in an odd way. The TD siblings used colloquial language to imply that their brother had an intellectual problem, but that they did not know why.

When the children spoke about their brother with ASD's special needs it was as if they were describing a frustrating aspect of their brother's character. They did not seem to understand that their siblings' special needs meant that their siblings experienced difficulties that they did not. These findings fit with Glasberg's (2000) findings that the siblings of children with ASD frequently do not have an age appropriate understanding of the child with ASD's difficulties.

**The children with ASD's interest in their siblings**

All the children with ASD gave behavioural indications that they were interested in their siblings. These included being in the same room as their sibling or watching their sibling. For example, according to his mother one of the boys with ASD did not interact with the other children at his school and would move away when another child came near him when he was outside. In contrast, at times he seemed to want to be with his TD sister. When his sister went outside to play, he would also go outside. When the ASD brother was watching his favourite bits of movies, he frequently looked over at his sister who was in the same room.

One set of parents said that their ASD son initiates rough and tumble play much more frequently with his TD older sister than with other children. These findings suggest that children with ASD maybe more motivated to interact with their siblings than they are with other children.

### **The siblings interacted together in situations other than play situations**

Although the focus of the current project was on sibling play, occasionally I arrived at the children's houses when they were having snack time. I observed that siblings interacted during their snack time.

The following incident occurred when I arrived early for a session and the children were finishing their afternoon tea. The boy with ASD ripped off a piece of his pancake and threw it on the ground.

**The TD girl points to the piece of pancake on the ground and says, “Go pick that up”. Her brother with ASD looks where she is pointing and goes, “Oh, oh, oh “. Their mother says, “What’s the matter Gracie”. The girl says, “Grant threw a bit of the pancake on the ground”. She turns to look at her brother who, with a smile, tears off another small piece of pancake and throws it on the ground. She smiles and says, “Two”. Her brother eats a piece of his pancake grinning as he does it and puts his hands on his hips in mock defiance and then turns his head. The girl laughs. Her brother turns around and smiles at her. Then he gets off his chair and walks in a circle with the same mock defiant attitude. She laughs and pats him on the shoulder.**

The children seemed to be enjoying their interaction at the table and it seemed more equal than their play interactions. There are research findings that sibling dyads, where one child has an intellectual disability (ID), interact more during non-play activities than during play activities compared to typical sibling dyads (Stoneman, Brody, Davis & Crapps, 1989).

Non-play activities include snack times and watching television. A possible reason for these findings is that fewer skills are required to interact in these settings (Stoneman, 2001).

## **Cluster Two: The Intervention Phase of the Project**

### **The TD children's responses to the intervention phase**

*The TD children seemed to have limited interest in discussing strategies and behaviours they could use to enhance play with their siblings with ASD*

There was a muted response by the TD children to discussions about ways they could help their sibling with ASD. The children listened but generally did not contribute ideas. Their parents reported similar experiences.

One of the TD sisters was initially resistant to my suggestions to help her play with her brother with ASD. In the first intervention session, she said a number of times, that she did not like playing with her brother. She would change the subject when I started talking about her playing with her brother with ASD. When I praised her for the skills, she had shown in getting him to play "Ring a ring a rosie", she denied ever playing the game with him. When I showed her the video of her and her and her brother playing" ring a ring a rosie "she dismissed it as "*not really ring a ring a rosie*".

Her mother said that she lacked confidence in her ability to play with her brother. The children's resistance to discussions about their sibling's special needs might have been because they did not find the topic interesting. It is also possible that they found the topic overwhelming and difficult.

***Recent events influencing their attitude towards talking about their sibling with ASD***

The children's willingness to talk about playing with their sibling with ASD often varied between visits. When the TD children had experienced recent unpleasant interactions with their sibling, they were more reluctant to talk about ways to play with their sibling with ASD than at other times. The TD girl in the following example had been happy to talk about her brother starting school in the previous visit, but on the day of this example, she did not wish to discuss playing with her brother. That day her brother with ASD had made a very public fuss at their school. In addition, other children at their school had commented about her brother's aggressive behaviour.

**I asked, "*Is this the kind of game you could play with Grant?*" She answered, "*Um, I don't know*". I said, "*Remember we are trying to think of things you could do with Grant, have you had any new ideas?*" The TD sister answered, "*Actually, no*". I then asked, "*What's it like having Grant at school now?*" The girl paused looks up at her sister and opened her eyes wide said, "*Um,*" and then paused. Then she said slowly, "*I don't know*".**

***The gender of the siblings influenced the discussions about playing with their siblings***

There were differences in the interests and behaviours of the TD siblings that seemed to be influenced by their gender and their age. All three TD girls were keen to talk about their friends. In contrast, discussions with the only TD boy stayed on the topic although he was generally very quiet in discussions. It is possible that the TD boy's behaviour was different because he was four years older than the TD girls were. Here is a conversation I had with one of the girls when I tried to discuss her play with her brother. This conversation is typical of conversations with the TD sisters.



**I said, “You were really good at getting Grant to play that game.” The TD girl said “What game?” I said, “The spider and the web.” She said, “Um”. I said, “It seems that when he cries if you ignore him he’ll come right. Is that right?” The TD girl said, “Um”. Then she said more enthusiastically, “You know once I was looking out for my friend and I was like, cos you know Gemma has a friend who always plays with her and I said ...”**

### **Responsive strategies**

#### ***In some instances strategy use did not result in the desired consequence***

Teaching strategies to the TD children did not always result in the expected outcomes. The TD children sometimes misunderstood the strategy. Sometimes the child with ASD did not respond to their siblings’ strategy use, which resulted in the TD children discontinuing their use of the strategy.

The first strategy I taught the TD children was to follow the child with ASD’s play. After talking with a TD sister about the usefulness of following her brother’s play, she went and played a board game with him. She took a passive role in the game allowing her brother to move her pieces and dominate the game. On a subsequent visit, I asked her what she had learnt she replied, “to let him win”. When I questioned her, further she said “do what he does and say words to help him”. Her understanding of following her brother’s play led her to take the passive role in the board game with her brother. The game was not enjoyable for her because her brother controlled and dominated the play.

The following incident occurred after I suggested to a TD sister that imitating her brother might be a useful strategy in their interactions. They were playing on a trampoline, covered in autumn leaves.

**The brother with ASD lies on his back; he has just tried to tackle his sister who has bounced away from his grip. He moves his legs and arms up and down**

**pushing the leaves aside. His sister lies down and copies the movement her brother has been making a moment before. He sees her lying on her back. He immediately crawls over to her and jumps on her.**

In the scenario above the brother with ASD's usual way of interacting with his sister was by jumping on her and engaging in rough and tumble play. Although, she tried to imitate him on a number of occasions, he did not respond to her attempts at imitation. Eventually she ceased trying to imitate him.

***Strategies were useful when they were used in response to a particular problem***

The strategies taught to the TD brother to gain the attention of his brother with ASD succeeded in getting the brother with ASD's attention. One reason for his success may have been that the TD boy being older than the TD girls was more able to implement the strategies successfully. Another reason may have been that the TD brother wanted to gain the attention of his brother with ASD and therefore he was motivated to try the strategies.

The TD brother had identified in our initial interview that playing with a ball was something he would like to do with his brother. The brothers were provided with identical balls to encourage engagement and the TD brother was encouraged to imitate his younger brother's actions. The boys were in their backyard and plastic cones had been placed in the middle of the lawn and at each end. Their mother and I were observing and prompting their play.

**Their mother says, "Get, Set, go..." The brother with ASD echoes her, "Go," and then the TD brother says, "Go". The boy with ASD glances at his TD brother and then dribbles his ball to the cones at the other end. His TD brother follows suit. The brother with ASD picks up his ball, runs back to the end they started**

**from, and taps the cone with the ball. The TD brother does the same and his brother watches him as he taps the cone with his ball.**

The boys' mother and I went inside and left the boys playing after five minutes. The boys played for about half an hour outside moving from playing with balls and cones to other games. The identical balls and the TD brother's imitation of his brother attracted the brother with ASD's attention. When the boys played with the balls, I observed more interaction between the boys than I had observed before. The ball game was the only occasion that I observed the boys playing an active game. The increased interaction between the boys may have been because they were playing active games. In the final interview, the TD brother said the identical balls game was the best thing in the project.

In another session the TD boy was taught to use playful obstruction, a strategy designed to get the child with ASD's attention (Ingersoll, Dvortcsak, Whalen & Sikora, 2005). The TD brother purposely crashed into his brother's toy car when playing cars a number of times while saying things like, "*Oh, no!*" This strategy also succeeded in getting his brother's attention and increased interaction between the brothers.

In the final interview, approximately six weeks after he had used playful obstruction, I asked the TD brother if he had used the technique again. He said that he had thought the technique had worked well but that he had not had a chance to use it again. There are a number of possible reasons why he may not have used it again. He may not been confident enough to use it again as we had only used it in one session. It is also possible that "playful obstruction" did not fit with the style of the brothers' interactions. Crashing toy cars is an activity that may be too young for the TD brother.

### **Ethical Dilemmas /Challenges in implementing the intervention phase**

#### ***Sometimes the needs of the children were in conflict with the design of the project***

Sometimes there was conflict between the needs of the siblings, which created a dilemma, as a decision needed to be made about which child's needs would dominate. The project aimed to meet needs of the TD siblings and needs of the sibling with ASD. Yet because the purpose of the project was to enhance the siblings' relationship there was a need in most discussions to discuss the child with ASD. The TD children frequently wanted to talk about aspects of their life that was important to them such as their friends at school that did not include their sibling. In addition, the child with ASD was frequently present when I spoke with the TD child.

Some of the parents commented in the final interview that their TD child would have liked the project to have more time with me without their sibling with ASD being present. A mother said that her TD daughter might have felt the project was still all about her brother. Her father said that his daughter sometimes said that she would have liked if we (her and I) had time together without her brother with ASD. Another mother said that her daughter had wanted me all to herself.

#### ***Encouraging the TD children to follow the play of a child when the child is domineering or unpleasant towards them is not in the best interests of the TD child***

Many researchers consider following the child with ASD's play to be an efficacious non-intrusive method of encouraging interaction between the child with ASD and a play partner (e.g. Wimpory et al., 2007). However, encouraging the TD sibling to follow the child with ASD's play was not always in the TD child's best interest. Sometimes the sibling with ASD controlled the play so that it was not fun for the TD child to try and be involved with them.

The following example demonstrates how sometimes the rights of the TD child to have pleasant fulfilling play conflicts with the practise of following the child with ASD's play. The incident also demonstrates that sometimes children need support so that both the TD child and the child with ASD can participate in an enjoyable game together.

I have observed the child with ASD, in this example, playing a number of previous board and card games. Each time he would control the games so that there was no real role for other participants in the game. I brought insect cards and a spider web to encourage the child with ASD to join in a game of hide and seek. I also brought pictorial rules to help him understand the roles in the game. His TD sister had identified hide and seek as a game she would like to play with him. An older sister of the target siblings was also willing to play the game. The brother with ASD took the insect cards and began shuffling them. I tried to go through the rules with him but he was not interested.

**I say, “*Now you give the spider card to Gracie*”. The child with ASD starts to cry.**

**I show him the cards and say, “*Which one do you want?*” He says, “*I don’t know,*” and throws himself wailing loudly onto the couch. An older sister and his TD sister and I play the game while he wails. (The video camera was recording in the lounge where he was during this time. The footage shows that he stops wailing when no one is in the room and that he begins again as soon as people can be heard approaching the lounge). **We played one round of hide and seek without him. I encourage him to come and count with me in the next round when I am in. His sisters encourage him to play and help him play. Eventually he participates fully in the game.****

By supporting the brother with ASD in the game, he was able to play hide and seek with his family. If the brother with ASD had played the game as he initially wanted to, his TD sister would have had a frustrating experience, making it less likely that she would want

to play a game with him again. It is unlikely that the TD sister, who was the focus of the project, would have been able to persuade him to play cooperatively with her, if an older sister and I had not been actively involved.

### **The project could harm existing relationships**

Findings from this project suggest that when a sibling intervention project occurs in the natural environment there is a risk of distorting existing relationships. In one of the families, the mother reported that the TD sister usually played with her next oldest brother not her younger brother with ASD. Their mother reported that the project meant that the older brother lost his usual playmate and that he sometime had difficulty occupying himself during my visits.

In this example, although I could not hear all that was said, it seems that the older brother is being excluded from the play between his TD sister and their brother with ASD because I am there filming them.

**The TD girl says something quietly to the older brother. He says “*why not?*” and she says something quietly. The older brother says, “*What did you do/ say that for?* He goes and gets off the trampoline. I say, “*Lyndon can play, that’s okay with me*”. He stands by the trampoline and says to his sister “*If mum heard you say that you know how much trouble you would be in*”. She replies defiantly, “*no*”.**

### **Unexpected outcomes could have a negative influence on the TD children**

Placing the project in the children’s natural environment also meant that outcomes could occur that may not have occurred in a more controlled environment. In the incident described earlier where the sibling with ASD told his TD sister to leave his bedroom, he had power over his sister because they were playing in his bedroom, that he would not have had in an intervention situated in a clinic or confined to a family room.

An incident that occurred after my first discussion session with a TD sister illustrates the influence of adult's behaviour on the behaviour of children with ASD. The TD sister went out to play on the trampoline and called her brother to come out and play with her. I encouraged her to call out to him and prompted her. The brother went over to their dog, I commented to him on the dog and asked the sister if she would like to come and pat the dog with us. She came over. The brother then indicated that he wanted me to go on the trampoline with him. Eventually both children got on the trampoline.

**They both start bouncing on the trampoline but the brother with ASD keeps reaching out to me. I encourage the TD sister to imitate her brother's bouncing. She does for about four bounces then calls out to her mother. She lies down on the trampoline while her brother looks out at me making animated upset noises. Their mother comes out and takes him inside to calm down. His sister and I remain outside. I can hear him making distressed noises. I say to his sister, "*Does that sound like Andrew's upset?*" She replies, "*Yeah, it doesn't matter, I don't care*".**

For the rest of the session she was not interested in playing with her brother. It seemed that her brother's preference that session for my company over hers made her feel less motivated to interact with her brother.

In the above incident, my enthusiastic prompting of the TD girl drew the child with ASD's attention to me rather than his sister, which meant that my behaviour did not facilitate the siblings interacting together but became a barrier to their interaction. My more animated behaviour may have been more appealing to the boy with ASD than his sister's behaviour as research has shown that children with ASD respond to animated behaviour (Wimpory et al., 2007).

### **Developmental influences on the outcomes of the intervention**

Research findings on the development of TD children suggest that expecting increases in play between the TD sisters and their brother with ASD may be unrealistic when the TD child is moving into middle childhood. I observed one TD sister and her brother with ASD; they had the longest observation period, over a period of six months. The TD sister's interest in playing rough and tumble with her brother declined over the observation period. She mentioned in one of our final sessions that now she preferred playing on the trampoline with her friends rather than with her brother. In our final interview I reminded her that she had told me at the beginning of the project that *"tag and tumble"* on the trampoline with her brother was one of her favourite things. She explained that she did not like *"tag and tumble"* anymore.

***"Yeah I hate it now". "I don't like doing anything with my brother actually ...maybe I don't". "I've got totally sick of it. I just end up with a big bruise on my head," and then she said, "Like I've got a friend next door and she doesn't really like being on the trampoline with Samuel so he can kick her over and stuff."***

It is possible that taking part in the project could have influenced her change of heart about playing *"tag and tumble"*. She may have tired of their play due to an increase in playing *"tag and tumble"* during the observation period of the project. By the end of the project, she was almost seven years old. Her statement may have reflected a developmental change in her play and companion preferences. Children in middle childhood prefer to play with their own sex and the games boys and girls tend to play differ (Carr, 2006). Research evidence suggests that the closeness of the relationship between the TD sisters and their younger brothers in the project was likely to be declining as the closeness of relationships in mixed sex sibling dyads declines in middle childhood whereas closeness in same sex sibling dyads remains relatively stable (Orsmond & Seltzer, 2009).



Two TD sisters were almost seven and the other TD sister was seven. This age is typically a time of developmental change. Children around the age of seven move towards preferring rule based games (Case-Smith & Kuhaneck, 2009). Children with ASD's play development is slower than TD children's and they usually remain fond of rough and tumble type play longer than TD children (Case-Smith & Kuhaneck, 2009). TD children in middle childhood are often less interested in playing with a sibling with ASD due to the difference in their play interests and levels (Harris & Glasberg, 2003).

### **Cluster three: Useful Components of the Project**

#### **Positive game experiences increased the likelihood that the children would spend time together**

When both children participated happily in a game or an activity there seemed to be an increase in warmth between the children, and the sibling with ASD was more likely to stay near the TD child. An example would be when the brothers played with the identical balls they continued playing together without adult input for approximately half an hour. These findings are similar to Baker's (2000) findings that once sibling dyads, where one sibling had ASD, had a satisfying play they were likely to continue playing together. My focus changed during the intervention from trying to teach the TD children new strategies to a focus on finding games and activities that would appeal to both siblings.

#### ***Some siblings enjoyed a simple rule based game designed to include both children's interest***

Two of the sibling dyads enjoyed playing "Trains and Fairies", a simple game designed to include both children's interests by individualising the cards used in the game. In the project all the boys had cards based on different coloured trains, two of the TD sisters had different coloured fairy cards and one sister had different coloured piggy bank cards.

I first introduced the game to the sibling dyad that included the boy with ASD who loved board games. When he played board games with other people, he seemed to make up rules as he played which resulted in unsatisfying experiences for his play partners. Both children enjoyed the game and played it many times. The following is an example of them playing “Trains and Fairies”.

**The sister passes the dice to her brother who throws a two and says, “*Two, Toby*”. He passes the dice back to his sister. She throws the dice. She says, “*no!*” and raises her hands above her head and brings them down on the board (she had rolled a number that she already had). Then she says, “*Grant’s turn*” and passes the dice to her brother. He throws and says, “*Three, no! I wanted Diesel*”. He passes the dice back to his sister.**

After playing the game, a number of times the boy with ASD spent the rest of the session with his TD sister and me. Usually he would have been playing in his room by himself. We read a book together and then the brother with ASD answered his TD sister’s questions as she filled in a form about him for the project. The siblings played the game, at their request, in other sessions and they played it out of session time as well. In my final interview with the TD girl, she confesses that she sometimes cheated in the game so that she could win. This suggests that she was absorbed in the game and wanted to win. In Baker’s (2000) study, both the typically developing children and the children with ASD were observed to cheat at times. In the final interview with the children’s mother, she reported that the board had fallen to pieces.

The game was trialed with all four-sibling dyads. One of the other dyads played the game a number of times successfully with support from their mother and me. They also played it again, with adult support, out of session time. The game was too difficult for one of the younger brothers to play but his sister played the game with me. The younger brother

watched some of our game and his father commented in the final interview that he thought the game was useful because his son became curious about something his sister was doing and he was interested in her actions. Generally, the younger brother's response to his sister was to try to play fight with her.

Dewey, Lord & Migall (1988) found in research on children's preference of materials for use in dyadic play children with ASD preferred rule bound games, such as snakes and ladders, whereas most other children preferred to play with dramatic materials. Rule bound games were most other children's second choice (Dewey et al., 1988). They speculated that the preference of children with ASD for rule bound games is probably due to the inherent structure of these games (Dewey et.al, 1988). Game play was associated for all children with the most positive scores on fun and involvement (Dewey et al., 1988). The two youngest children with ASD in their study, who were under seven years old, did not play the games, as they did not understand the rules.

The children, in the current study, did try to play other rule-based games such as snap but the children with ASD did not understand the rules correctly. This suggests that some young children with ASD need very simple games to play. According to parent report, the only rule based game that any of the siblings played together out of session times was "Trains and Fairies". A possible reason may be that because the children with ASD did not understand the rules properly these other games were not fun for the TD children.

### **It was important to find games or activities that both children enjoyed**

The choice of game or activity proved to be very important in determining whether the children would play together or not. Researchers have also found with TD children that "The ability of siblings to play together depends, at least in part, on their skill in selecting activities in which both children can participate (Lobato et al., 1991; Stoneman et al., 1987)" (Stoneman, 2005, p. 341).

An example of a game that encouraged both siblings to participate was the limbo game. One of the TD girls loved music and dancing so I brought CDs of instrumental dance music and two identical ribbon sticks with ribbons to her house. Her younger brother also liked music. The sister strung the ribbon between two seats and alternated between jumping over the ribbon and going under it. Her brother went under it a number of times.

**The TD sister went under the ribbon and then turned around and went under again. Her brother was standing nearby. Their mother said, “*Do you want to go under Andrew?*” He bent his head forward and went under the ribbon. He then came to where I was standing with the camera. His sister came over to him, put her arm around his back, and guided him under the ribbon.**

When I left shortly, after they were still playing together which had not happened before in any of my previous visits. It was the first time I had known the TD sister to play with her brother by choice. Previously their only play together had been when the TD sister was prompted to play with her brother. Their mother reported in the final interview that the TD sister and her friend played with the ribbon sticks another time and the younger brother joined in. The limbo game also demonstrates the ability of children to invent their own games.

An example of a game that did not appeal to both children and did not result in mutual enjoyable play was when I introduced “Trains and Fairies” to the sibling brothers. The brother with ASD had the requisite skills to play the game. The TD brother did not like the game because he felt it was too young for him. He was the captain of his school chess team and liked challenging games. The TD brother attempted to play the game but his brother wandered away.

When I introduced a similar game to the “Trains and Fairies” game that used dinosaur cards to the sibling dyad that most liked the “Train and Fairies” game the younger brother was not interested in trying the game. He was not interested in dinosaurs.

***Children were more likely to participate in games and activities if they were encouraged to do so by someone else***

In most instances, as in the above incident when the mother prompted her son to be involved, there was some form of adult promotion of the children’s play. Most successful new play seemed to be dependent on an adult prompting and encouragement.

***The siblings enjoyed active games***

The children played less active games during the intervention phase. It was winter and most active games are outside games. However, as in the observation period, the children seemed to enjoy the active games and interacted when playing active games. One of the TD sisters said that the balloon game was her favourite game in the project. The balloon game involved seeing who could keep their balloon in the air longest. One set of sibling dyads enjoyed a game of bouncing on their moon hoppers. When they nearly collided, they both laughed.

During the project period the TD boy had his eleventh birthday and was given a Nintendo Wii. The Nintendo Wii allowed him to play active games with friends and his brother with ASD on the Nintendo Wii. When the boys played the Nintendo Wii they were side by side so playing the game did not seem to encourage joint attention. The Nintendo Wii became the favourite game of the boys to play and they both enjoyed it. The boy with ASD used soccer balls cones to copy a game from their Nintendo Wii. The brother with ASD had watched his brother play the games in the beginning but was beginning to play games with him on the Nintendo Wii by the end of the intervention period.

## **Other games and activities**

### ***Arts and crafts activities did not promote interaction between the siblings***

Arts and craft activities, such as play dough, bread dough, face painting and drawing did not seem to interest the children with ASD. This finding supports research findings that children with ASD have lower preferences than TD children for drawing and colouring and figurine play (Case-Smith & Kuhaneck, 2009). Musical instruments also failed to promote play between the siblings. One of the children with ASD played a cymbal loudly for some time, which annoyed his other family members.

I made books, using characters that the children had identified liking, about the games that I introduced to the children, to support their game play. Some of the TD children and some of the children with ASD enjoyed the books. One of the TD girls said that she would read the book to her brother. Her mother reported that her daughter did not end up reading it to her brother, as he was not interested. Her mother, however, was delighted that her daughter had wanted to read to her brother.

## **Providing information encouraged positive attitudes towards their sibling with ASD by the TD children**

### ***The TD children displayed a positive attitude towards their sibling with ASD after participating in the emotion component***

The three girls all seemed motivated to try to play with their brother with ASD after the emotion component. Possibly, because they enjoyed the component and so were feeling happy or possibly because reflecting on their own feelings made them feel more positively about their brother with ASD. The TD brother chose not to participate in the emotion component.

After participating in the emotion component one of the TD sisters, for the first time, thought of an activity, bouncing on moon hoppers, to play with her brother. She went and got a moon hopper for herself and her brother and encouraged him to play with her. The emotion component session focused on the TD children and their feelings without reference to their sibling with ASD.

***Descriptive information helped promote play***

In the descriptive information sessions, the TD siblings identified common interests with their brother with ASD. For example, one sister identified that playing on the trampoline was both her and her brother's favourite activity. After our discussion was finished, the TD sister encouraged her brother to go and play with her on the trampoline. They played together on the trampoline for over 20 minutes that day.

The TD girls were happy to fill in forms about themselves and their brother in descriptive information sessions although the TD sisters spent more time filling in forms about themselves than in filling the forms in about their brother. The TD brother did not fill in the forms instead; we discussed similarities between himself and his brother.

***Resources for the siblings of children with ASD promoted the TD children to reflect on their relationships with their siblings with ASD***

Comments made by the TD children and their parents suggested that the resources prompted the TD siblings to reflect on their relationships with their siblings with ASD. The resources used were books for the siblings of children with ASD and a DVD "Understanding Brothers and Sisters on the Autistic Spectrum".

I read "All Cats have Aspergers" (Hoopman, 2006) with one of the TD girls. She discussed the concepts in the book. When we had finished reading the book, she said that sometimes she was mean to her brother. She said she did not know why. Her comment

suggests that she was thinking about the information in the book and reflecting on her relationship with brother.

One of the mothers said that the DVD “Understanding Brothers and Sisters on the Autistic Spectrum” (Coulter, 2007) provided a good focal point for a half hour family discussion between her five TD children. Their family identified with the families on the DVD. Their mother reported that seeing the DVD took the scariness out of what might be coming up in the future for the family with their brother with ASD..

***The video footage was useful in providing positive feedback***

The video footage of the TD children was useful for showing the children the positive things they did with their sibling with ASD. For example when I showed one of the TD siblings, her success in getting her brother to play on the moon hoppers she went and encouraged her brother to play with her again. The TD children responded well to positive feedback.

**The contribution of parents and non-involved siblings to the project**

***Including parents in the discussions was useful***

The children seemed to respond well when their parents took part in the discussions. Discussions that were prompted by concerns the children made were useful, especially discussions that included their parents.

When one of the TD sisters and I watched some video of her brother pushing her away, the TD sister said “*I wish he would not push me in the private parts*”. We discussed what to do when her brother pushed her in ways she did not like with her mother. Her mother reassured her that in such circumstances she could tell her brother to stop and push his hand away. Her mother said that is what we usually do. The TD sister commented that she did not know that is what they usually did. Being involved in the project gave the TD sister an



opportunity to talk with her parents about things that concerned her. It has been documented that the parents of children with ASD often presume that their TD sibling has a better knowledge of the situation than they do (Glasberg, 2000).

All the parents said that they found the discussions useful. One mother said that she liked being around when we had discussions as she knew what we were talking about.

***Parents and non-involved siblings supported play between the two siblings involved in the project***

One consequence of the project being set in the natural environment was that the children's family members were also involved in the project. The children's parents and their other siblings were supportive of the project. Parents would frequently prompt their children. Sometimes the children's parents would become involved in activities supporting their children by prompting their children and praising them. When I introduced the "Trains and Fairies" game to one set of siblings, their mother supported the child with ASD in playing the game and I encouraged the TD child.

The TD siblings of one sibling dyad sometimes participated in the activities and games. They would encourage the child with ASD in their play and support the TD child. After we played the spider and web game the target sibling's 16-year-old brother tried to get to his brother with ASD to play the spider and web game.

**Cluster 4: Findings from the Final Parent Interview**

**Having a person come to the house and work with the TD child was helpful**

The parents reported having someone, come to the house to work with their TD child was useful. One mother said that she felt her daughter was more receptive to information

from me, as a person from outside their family, than she would be to information coming from her mother.

Parents reported that they found the resources useful and the opportunity to talk with another adult about their children useful. A mother commented in the final interview that she found the extra tips and information that she got from being involved in the project useful.

***Parents' reported improvements in the attitude of their TD child towards their child with ASD***

In the final interview, all the parents commented that their TD child's understanding of their sibling with ASD had improved and that the children's increased understanding had led to more positive attitudes towards their siblings with ASD. All the parents said that it was important to them that their TD child's understanding of their sibling with ASD increased. One parent reported that her TD child was more confident with her brother with ASD and would approach him directly whereas before she would communicate with her brother through her mother.

One mother reported that although her children played together less after the project than before that the quality of their play had improved. She attributed the increase in the quality of the play in an improvement in her daughter's attitude towards her brother.

***“She enjoys playing with her brother a lot more now. When she is at home there is a lot of distractions which means that she often has other things to do than play with her brother but when she has to she is a lot more willing.”***

In the final interview another set of parents reported that both the quality and quantity of play between their children had improved somewhat. One father said that his TD daughter was happy about the things she learnt even though she may not have seemed so at the time. He said that she would go away after a session with me, think about what we talked about, and then try things.

One mother said of her daughter, “*She just does not seem to be so ‘anti’*”. Her mother gave this example of her daughter’s changed attitude. Her daughter, her daughter’s friend, and her son with ASD were playing on the water slide. The daughter’s friend turned the water slide off part way through the boy with ASD’s turn. The friend climbed up the water slide and the boy with ASD, who was at the top of the slide, pushed her back down the slide. The TD sister laughed and said, “*Good on you Andrew, she shouldn’t have turned it off on you*”. Their mother said that once her daughter would not have taken her brother’s side in any situation.

One mother reported that her daughter said one day when she was getting frustrated trying to get her brother involved in a game, “*Suzanne needs to come back. Andrew and I are not playing well*”. This TD girl at the beginning of the project had said that her brother and her never played together and had mentioned a number of times said that it did not bother her that they did not play together.

### ***The TD children became more tolerant of their siblings with ASD***

All of the parents reported that their TD children were more tolerant with their sibling with ASD. One mother reported that her TD daughter no longer gets angry when her brother with ASD plays with her toys and is more accepting of her brother.

***“Play usually begins with Grant wanting to play with Gracie’s toys. Once she would not like it but now she lets him play. Gracie has a better understanding of Grant now and is more patient. Grant generally only plays with Gracie’s toys for a small amount of time.”***

Another parent said that his TD daughter was now “*more tolerant of his (her brother’s) differences and more forgiving*.” and that she does not tell her brother to “*stop*” as much as she used to. Another mother gave an example of how her son with ASD had been irritating her daughter by kicking her feet and her daughter had made a comment but did not

get upset. Her son laughed. The mother said that before the project her daughter would have got upset and would have been in tears.

***Being involved in the project was helpful in meeting some of the participating families' individual needs with their children***

The different children and their families' needs from the project varied in some ways and so there were some individual outcomes. The TD brother's mother said that being involved in the project had helped her TD son cope with his feelings of embarrassment at school about his brother's behaviour. In discussions with the TD brother and his parents, we had talked about the TD brother's difficulties coping with having his brother with ASD at the same school. The boys' teachers were also aware of the problems and had been helping the TD brother deal with his brother's behaviour at school.

In another family, their TD daughter and their son with ASD did not play together inside at the beginning of the project and occupied different areas of their house. Their mother commented that she felt the project had helped bring the family together as a whole as their involvement in the project had made it possible for the siblings to be together.

In conclusion, the parents all expressed their satisfaction with the outcomes of the project.

***Parents' suggestions for improvements***

In the final question put to the parents in their final interview was "how the project could be improved?" The mother of the older sibling who felt left out when his two younger siblings were involved in the project, suggested a meeting be held with the children's entire family before the project began. She said that a meeting would make all the family members feel involved and the roles of family members could be discussed in the meeting. Another mother thought that it would be useful if the project were presented in a group format. She

thought it would be useful if the TD siblings meet other and talked with other TD children with siblings with ASD.

One parent said that her children's involvement in the project had made her aware of the potential of the sibling relationship. She said that she wished that the project could have been longer so that there would have been more opportunities to work with the children. She said that although she thought being involved in the project had benefited both her children she thought that a longer project could "*make a huge difference*" in the children's lives. The same mother said that it would have been useful if the project had been coordinated with a person who was working with the child with ASD. The child with ASD could be supported by their worker in interactions with their TD sibling.

### **Summary of findings**

This project generated findings on the existing relationship between the children. The TD children were observed to already have a good range of skills to communicate clearly with their siblings with ASD and to extend their play interactions. The TD children expressed and displayed mixed emotions towards their sibling with ASD. The children with ASD displayed behaviours that indicated that they were interested in their TD siblings. It seems that three out of the four sibling dyads did not play together very frequently at the beginning of the project.

Findings from initial stages of the intervention suggested that the intended plan for the project did not always benefit the TD siblings. Some of the TD siblings were more interested in talking about themselves and their friends. Teaching strategies did not always work as intended. In addition, there were unanticipated findings on the influence of the intervention on a non-involved sibling.

Findings from the middle and later part of the intervention suggested that siblings can have fun interactions when playing very simple games that have elements that appeal to both

siblings. Findings also suggest that providing information on the child with ASD's strengths and difficulties and providing emotion information may positively influence the TD child's attitude to their siblings with ASD. There was evidence at all stages of the intervention of the influence of adults on the children's interactions.

In the final interview parents reported that their TD children's understanding of their sibling with ASD had improved and that they had become more tolerant of their sibling with ASD. All parents reported that the quality of play between their children had improved.

The meaning of these findings for the TD children and their siblings with ASD will be discussed in the findings section. The findings will be considered in the context of relevant information from the literature review. This discussion will conclude with recommendations for future research.

## **Chapter 5. Discussion**

The ultimate aim of this project was to help the TD child have successful play experiences with their sibling with ASD. The reviewed research suggested that for the child with ASD participating in enjoyable play with another child would enhance children with ASD's development. In the final interview, parents reported that the quality of their children's play had increased and that their TD children were more tolerant of their sibling with ASD's behaviour. It seems that positive outcomes were mainly generated by the components of the project that were included to increase the motivation of the TD siblings to interact positively with their sibling with ASD. The current project found evidence that providing support to the TD siblings can improve the play interactions between the siblings. In this discussion, the outcomes will be presented along with findings of important aspects that emerged during the research that influenced the play interactions between siblings. Key aspects include the focus on TD children, helping the TD children to feel special, facilitating simple play activities that appeal to both children, embedding the project in the children's natural environment, enhancing the TD children's understanding of their sibling with ASD, and the role of the children's parents and other siblings.

### **Findings on Costs and Benefits to the TD Children from being Involved in a Sibling Intervention**

In this section findings of the research will be presented alongside relevant literature. Siblings seem a logical choice to use in social interventions with children with ASD because of the time they spend together and their close relationship (Brunner & Seung, 2009). Research findings that the siblings of children with ASD's well-being may be more vulnerable to environmental factors than other children's suggests the impact of any intervention on the sibling's well-being must be explicitly examined (Macks & Reeves, 2006).

It was initially expected that the TD siblings would benefit from increases in the social skills of the child with ASD. However, findings on the consequence of participating in the project for the TD siblings identified potential problems in using siblings in interventions. In the current project, a non-involved sibling felt rejected by his sister, his usual playmate, as she did not play with him when she was involved in the project sessions. Another potentially harmful incident occurred, when encouraging the TD sibling to use the responsive strategy, following the child with ASD's lead, resulted in the TD sibling's thinking that it was acceptable for her sibling with ASD to totally dominate and control their play.

Although similar incidents could occur in peer interventions, the existing relationships between the siblings, the important roles siblings play in each other's lives and the placing of the intervention in their homes, meant that the consequences of such negative incidents were likely to be more severe. There was evidence that the TD children felt pressure to play with their siblings through their involvement in the project. This was illustrated by the example of TD children only beginning to play with their sibling with ASD when the camera came out to film them.

Findings from the project suggest that the costs to the TD sibling of being involved in a project can outweigh the benefits when a project focuses on the child with ASD and their relationship with the child with ASD. Research results and comments by the TD children and their parents, showed that a need of the TD children was to feel as important as their siblings with ASD (Hutton & Caron, 2005; Meirsschaut et al., in press). Discussions that revolved around the child with ASD when the TD girls seemed to want to talk about their relationships with their friends risked reinforcing the idea that the child with ASD's needs were more important than the TD child's needs.

Findings from the project suggest that, in order to ameliorate possible negative impacts on the sibling relationship, it is important to consider the existing relationship and the



history of the siblings. In this research, there emerged evidence in the existing relationship of the siblings that the TD children felt mixed emotions for their siblings with ASD. These results are similar to the findings of other research (e.g. Bevan-Brown, 2004). All the TD children demonstrated affection for their siblings with ASD. Research results and comments by the TD children and parents in the current project also suggest that TD children frequently have feelings of resentment over the extra parental attention that their siblings with ASD receive. This result reflects findings in other research (Hutton & Caron, 2005; Meirrschaut et al., 2010; Rivers & Stoneman, 2008).

Rivers and Stoneman (2008) found that when TD children were dissatisfied with their parents giving more attention to their sibling with ASD, their relationship with their sibling suffered. This suggests that there is a danger that the relationship between the siblings may suffer, if an intervention reinforces the TD child's feelings that their sibling with ASD gets more attention than they do.

Some of the feelings the TD children had about their sibling with ASD are likely to be due to their sibling with ASD being their younger brother rather than due to their sibling's ASD. As researchers have reported, sometimes the irritation that older siblings of children with ASD can feel for their sibling with ASD is the commonplace irritation of an older sibling with a younger sibling (Dodd, 2004).

Findings also suggest the importance of considering the TD children's changing needs when designing and evaluating a sibling intervention. One of the TD girls, whose parents reported satisfaction with the outcomes of the project and increases in their children's quality of play, clearly articulated that she was less keen on playing rough and tumble games with her brother than she had been at the beginning of the project. Her parents had mentioned in the initial interview her declining interest in playing rough and tumble with her brother.

Research suggests that the gap between the play interests of TD children and their siblings with ASD widens as the TD children move into middle childhood (Harris & Glasberg, 2003).

These findings on the possible costs to a TD child of their involvement in a sibling intervention emphasise their needs to feel special and for all aspects of the intervention to be considered from their perspective as well as that of their sibling with ASD.

## **Outcomes of the Intervention Components**

### **Participating in the emotion component made the TD children feel special**

The emotion session focused on the TD child and may have made them feel special. All three girls, immediately after the session, seemed motivated to play with their brother with ASD and all three succeeded in having quality play with their brother with ASD after the session. The reason for the girls' positive attitude to their siblings with ASD may have been that the content of the session helped them feel positive about their siblings with ASD. It is also possible that the three girls were feeling positive because the sessions focused on them and their feelings. (The TD boy chose not to participate in an emotion session).

### **Teaching the TD children responsive strategies did not result in the expected enhancement of the children's interactions**

It was initially thought that it would be the TD children's use of new responsive strategies that would improve the interactions between the children and provide benefits for both children. Both peer interventions for children with ASD and most other sibling interventions have taught TD children skills and strategies to encourage the participation of the children with ASD (eg. Celeberti & Harris, 1995; Tsao & Odom, 2005).

Responsive non-directive strategies have been successfully learnt and applied by the parents of children with ASD resulting in developmental gains in social and language skills by their children (Girolametto, et al., 2007; Mahoney & Perales, 2007). TD children have learnt and applied responsive strategies in their interactions with their siblings with Down Syndrome promoting the development of the children with Down Syndromes' communications skills (Trent, et al., 2005; Trent-Stainbrook, et al., 2007). However, in this project the children generally did not persist in the use of the taught responsive strategies.

There are a number of possible reasons why the TD children did not persist in their use of the responsive strategies. The first is that generally their siblings with ASD did not respond to their use of new responsive strategies. Children with Down Syndrome are more likely to respond to their siblings' responsive strategies than children with ASD (Knott, et al. 1995). Parents are more likely to persist in their attempts at using responsive strategies than children are, and are more likely to use the strategies effectively. In other sibling interventions for children with ASD, strategy use has been supported by parental prompting and reinforcing (eg, Celeberti, 1993; Strain & Danko, 1995; Tsao & Odom, 2007). The TD children, in the current intervention, may have needed more adult support than they were given to learn and use the strategies.

As has been reported earlier, a conflict was identified in the project between the needs of the TD children to feel that they were the focus of attention and the need to discuss their sibling with ASD. Promoting the siblings' use of responsive strategies required a focus on discussing their sibling with ASD. The experience of conducting this intervention with the siblings of children with ASD suggests that it is difficult for a project to support equally the well-being of both siblings if a major focus of the project is the direct promotion of the TD siblings' use of strategies.

In addition, one of the findings of this project was that all the TD children already had existing skills in interacting with their sibling with ASD and in extending their interactions as has been documented in previous research (Knott et al., 2007). The skills that the children were being taught may not have fitted with their natural style of interacting with their siblings as well as their existing skills did. The findings from this project suggest that it is more important that the siblings of children with ASD be supported in their use of their existing skills than taught new skills.

### **Games and activities**

There appeared to be increased warmth and positive affect between the children when the children successfully played a game together and they were more likely to continue interacting together after a successful game. These observations concur with Baker's (2000) findings that successful participation in a game increases siblings' motivation to play with each other and improves the attitude of the TD sibling towards their sibling with ASD.

All the children seemed to enjoy active, gender-neutral outdoor games, and these games encouraged interactions. Previous research has also documented that a child with ASD is more likely to interact when involved in active play (Wimpory, et al., 2007).

Finding indoor games and activities that encouraged interactions between the siblings was more difficult. The indoor games that resulted in quality sibling interactions were extremely simple games that appealed to both siblings' interests. The findings suggest that the motivation and enthusiasm of the TD sibling is crucial in the success of games. One sibling dyad interacted successfully when playing the limbo with music and ribbon sticks because the TD girl loved the music and the game and was happy to make an effort to include her sibling with ASD in the game.

The findings that two sets of sibling dyads enjoyed playing a very simple board game "Trains and Fairies" fits with findings that children with ASD frequently enjoy rule-

bound structured games (Dewey, Lord & Migall, 1988). “Trains and fairies” was designed with personalised cards to provide motivation to play for both the TD sibling and the sibling with ASD.

### **Information component**

Discussions with parents and the TD children indicated that the TD children did not have an age-appropriate understanding of their sibling with ASD’s strengths and disabilities at the beginning of the project. This finding concurs with Glasberg’s (2000) finding that the siblings of children with ASD frequently do not have an age-appropriate understanding of ASD.

All parents reported in the final interview that their TD children’s understanding and tolerance of their siblings with ASD had increased. Information was provided to the children in a number of ways: by helping the children identify similarities between themselves and their siblings, providing them and their parents with age-appropriate books and a DVD. The children and I, and frequently their parents, discussed topics identified by the children. It was found early in the intervention process that discussions focusing on the child with ASD, or their relationship with them, that were not initiated by the TD child were counterproductive.

### **Advantages of embedding the intervention in the natural environment**

Embedding the project in the natural environment provided evidence of the conditions under which siblings were more likely to play together. The project found that the siblings were more likely to play together if they were outside, especially if they had outdoor equipment such as a trampoline, possibly because the children were more likely to be involved in active play if they were outside.

When the children were inside, play sometimes occurred in bedrooms, which meant that the bedroom owner had more power to control interactions. In some of the families, the siblings tended to inhabit different areas of the house, which tended to discourage interactions

between them. Many of the inside toys were gender-specific toys. These findings suggest that siblings' play together could be encouraged by families providing outdoor play equipment for their children and encouraging play in the communal areas of their homes by providing games and activities that are likely to appeal to both siblings.

Working in the children's home environment enabled other family members to be involved in a natural way that could be maintained. In every home, the parents became involved at times in the project, sometimes they supported their children in their interactions, and sometimes they joined in discussions with the children and me. In the one family where there were siblings older than the siblings involved in the intervention, the older siblings joined in some games. The support of family members not directly involved in the project enhanced the project.

### **The role of adults in the project**

Findings from this project emphasised the importance of adult facilitation of children's play and the importance that adults' behaviour is facilitative rather than intrusive. Previous research has suggested that the style of adults' behaviour exerts a strong influence on the interactions of children with ASD with other children (Anderson, et al., 2004; El-Ghororay & Romanczky, 1999).

Adult behaviour that encouraged the children to play by prompting and praising the children seemed to be an important factor in helping the children to play unfamiliar games and activities. In addition, an incident when animated adult behaviour drew the child with ASD's attention to the adult and away from their siblings had similarities to descriptions by El-Ghororay & Romanczky (1999) of intrusive adult behaviour, which seemed to stifle interactions between children. The findings of this project concurred with the findings of previous sibling interventions of the importance of adult involvement to encourage interactions between the siblings (Strain & Danko, 1995; Tsao & Odom, 2006).

In the final interview, the parents reported that having an adult from outside the family working with their children was useful as the children tended to take more notice when a non-family member adult talked with them. The praise of a non-family adult seemed to positively influence the TD children's behaviour.

### **Social validity**

Parents' comments both in the initial interviews and in the final interviews indicated that they valued the project as an opportunity for their TD sibling to have some special attention and to be helped to understand their sibling with ASD's difficulties. All of the parents reported that they were happy with the outcome of the project. It seemed from the parents' comments that increases in the quality of their children's play was most important to them. The parents' comments indicated that changes in the quantity of the children's play together were not as important to them.

When the TD children were asked what they liked about the project, they all mentioned their favourite game – for example one child liked the balloon game and another mentioned a soccer game. All the parents commented that their TD children had loved being involved in the project. In addition, they said they felt that their children with ASD had enjoyed the project. It was noticeable that the children with ASD were more likely to be in the same room as their sibling and I and to take an interest in what we were doing as the project progressed.

### **Limitations**

All of the findings in this project are preliminary findings. The project involved a small number of children and their families. Three of the TD children were girls of a similar age and one was a boy who was 4 years older than the girls were. A number of the findings for the boy differed from those of the girls suggesting that the findings were influenced by

age and gender. Many of the findings may be limited to girls of certain ages. Likewise, the boys with ASD were all of a very similar age although they differed significantly in their language acquisition and joint attention. In addition, although statistical details about the families were not gathered, given the small number and method of recruitment, they are unlikely to be representative of the range of families with children with ASD.

Although, this project was embedded in the children's natural environment, the presence of a researcher influenced the behaviour of the children and hence the project's findings. The intervention consisted of many components. The reason for the number of components was to increase the likelihood that the intervention would have positive outcomes for the children who gave their time to be involved in the intervention. However, the number of components, the limited time of the intervention, and the flexibility of the intervention meant that in this project a thorough investigation of the influence and effects of each of the components was not able to be undertaken.

## **Conclusion**

This project's findings support the findings of Dodd (2004) who found that when individual family members, including siblings, of a child with a disability, have their needs met, the child with the disability benefits. The project's findings suggest that working with the TD sibling can benefit both the TD sibling and the sibling with ASD. Although all the TD children in this project seemed to be well-adjusted happy children, this project demonstrates that having an outsider providing support to the TD siblings of children with ASD is useful to the children, their siblings, and their families.

One of the findings of this project is that enhancing the attitude and feelings of the TD children towards their siblings with ASD seems to be more important than teaching them to use particular strategies with their sibling with ASD. The findings from this project suggest the importance of making the TD children feel special. Further, the observations from this



project lend support to the findings of previous projects that the quality of the interactions between siblings is more important than the quantity of the interactions between siblings (Tsao & Odom, 2006).

The evidence from the findings suggests that the active ingredients in this project may have been adult attention, information on the child with ASD's difficulties, emotion information, mutually pleasurable interaction in games and activities, and adult facilitation of interactions. The current project found that providing opportunities for the siblings to enjoy interacting together and facilitative support when they were playing together produced quality interactions between the siblings. These findings lend support to other researchers' findings on the benefits of facilitating interactions between TD children and children with ASD rather than on training the TD children to interact with children with ASD (e.g. Baker, 2000; Koegel, et al., 2005). In addition, the findings suggest that the TD children's increased understanding and appreciation of their sibling's strengths and weaknesses may have improved the quality of the children's relationships. Observations from the project also concurs with Rivers & Stoneman's (2008) findings that sibling relationships, between siblings where one child has ASD, are better quality when the TD sibling has high levels of persistence. Rivers & Stoneman (2008) hypothesised that the link between high persistence levels in TD siblings and better quality sibling relationships may be due to the ability of the children to cope with annoying and disturbing behaviour.

It seems likely that the attention given to the TD child, their participation in the emotion component and the praise they received may have enhanced the TD child's positive self-concept. Gousmett (2006) found a positive relationship between the positive self-concept of the TD child and the child's relationship with a sibling with a developmental difficulty. The findings of this study suggest that enhancing a TD child's self-concept may enhance their relationship with their sibling with a developmental disability

Placing the intervention in the children's natural environment, without tight experimental control, highlighted the importance of the children's families. Findings from the current project suggest the existing unique relationships of siblings mean that it may not be accurate or useful to consider TD siblings as a special subset of TD peers. The findings from the project demonstrate that to meet both children's needs in a sibling intervention the project has to be examined from the TD child's perspective as well as from the perspective of the child with ASD. Research results and the findings of this project demonstrate that for a project to be ethical and effective, the project needs to benefit both siblings.

Finally, the findings indicate that it is possible to tailor sibling interventions so that the TD child feels that their needs are as important as their siblings and to help the TD child experience successful play with their sibling with ASD.

### **Further Research**

Research that compares the influences of the separate components, such as teaching the TD children strategies to use with their sibling with ASD, would be useful in isolating the essential ingredients in a sibling intervention. Further investigation of what aspects of the project promoted the TD children's understanding of their sibling's strengths and weaknesses, given the important role that increased understanding seems to have played in the current project, would be useful. Teaching TD children strategies and skills to use with their siblings with ASD whilst they are interacting with their sibling, as is done in milieu teaching, could be a useful tool to investigate (Brunner & Seung, 2008). The important role which adults, especially parents, seem to play in facilitating play between siblings suggests that research on the type of parental and adult behaviours that most effectively facilitates play would be valuable.

Further research on what works best for different age groups and the different genders is needed. The responses of the TD girls to the emotion component suggest that research on the outcomes of increasing TD children's emotion knowledge would be constructive.

Examining the effect and outcomes of this project by taking the perspective of the TD child suggests the need for more research on the effect being involved in sibling interventions has on the TD children and their wider family. The findings from this project support considering the influence of interventions from both the participants' perspective, and from the perspective of those closely involved with the participants in interventions.

It is likely that many of the findings from this project would be the same for other sibling dyads where one sibling has a disability and some of the findings would be the same for TD sibling dyads. There is need for research on the long-term effects of being involved in a sibling intervention for TD siblings, siblings with ASD and their families.

Finally, it is recommended that in future sibling interventions in the natural environment that all family members who share the home environment with the child with ASD are included in the initial discussions, and that future interventions are individualised for different families' individual needs.

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## **Appendix A**

### **Approval Letter from the University of Canterbury Human Ethics Committee**

Ref: HEC 2008/109

14 October 2008

Ms Suzanne Neame

School of Educational Studies and Human Development

UNIVERSITY OF CANTERBURY

Dear Suzanne

The Human Ethics Committee advises that your research proposal “Helping children to play with their siblings on the autistic spectrum” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 14 October 2008.

Best wishes for your project.

Yours sincerely

Dr Michael Grimshaw

*Chair, Human Ethics Committee*

## **Appendix B**

### **Information Letter for Parents**

**School of Education Studies and Human Development  
University of Canterbury**



### **Information Sheet**

Dear .....

My name is Suzanne Neame. I am a student completing the 5<sup>th</sup> year of my Master of Education in Child and Family Psychology. I am researching the effectiveness of a training course to help older siblings of children with Autistic Spectrum Disorder play with their sibling with ASD. The older siblings will be between the ages of 5 and 10 and the younger siblings will be between the ages of 3 and 6.

The purpose of this letter is to provide families, who may be interested, with an overview of the project and details of what will be required of them should they take part. If after reading the following information, you feel that the project might be appropriate for your family, please ring me, Suzanne Neame at 03 3499764 or on 021 269 6088 ( mobile phone ) or email me at [smn15@student.canterbury.co.nz](mailto:smn15@student.canterbury.co.nz) and we can meet and discuss the project further. If you are interested in taking part, I will need to get some further information about your child with ASD from you and possibly from the professionals involved. Before I speak with anyone else, I will check with you and get your written consent.

### **About the Project**

Play between siblings strengthens their relationship. Play is important for all children in the development of social and communication skills. The challenges typically faced by children with ASD can make play with them a frustrating experience for other children. This

project aims to make it easier for the siblings to play together by providing the older child with appropriate information and skills to facilitate interactions with their sibling.

### **What is involved?**

- An initial meeting with you to find out some more about you and your family and your children's development, we will go over the project in detail, check you are comfortable and that your children meet criteria for being involved. If so, I will ask you to find out if your children are interested. During this meeting I will show you any materials I will use and get your ideas about your children's play.(approximately 1 hour)
- If your children are interested in being involved, I will meet with your older child to discuss the play-training and meet your younger child. (approximately 15 minutes).
- Next we will meet again to discuss any further information I might need to get. I will meet with your older child to talk about playing with their sibling and meet your younger child. (approximately 40 minutes).
- Over the next 3 to 5 weeks, I will come to your house twice a week at an agreed time. I will film the two siblings together in the same area for 15 minutes. This will give me baseline information on how they interact. (approximately 20 minutes)
- For the next 7 weeks, I will come to your house twice a week and each time I will spend 10 minutes with your older child. I will talk to him/her about having fun playing with their sibling and the challenges they face in doing so. This may involve me reading a story to your child; reviewing previous videoed interaction with them and practising some ideas for them to use with your younger child. I will again video the children together for 15 minutes.  
(approximately 40 minutes)
- After 7 weeks, the older child and I will choose our favourite bits from the videoed interactions to make a new video that the child will get to keep as a record of the project.  
(approximately 40 minutes)
- At the completion of the project, you and I will meet to discuss how you felt the project went and I will ask you to complete a short parent satisfaction survey. Your older child will again be asked about playing with their sibling and for their thoughts about the play-training.  
(approximately 30 minutes)

### **What are my rights and my children's rights if I allow my children to participate in this study?**

It is your choice whether you allow your children to participate in this study. If you choose to allow them to participate you can withdraw with your children at any time. Your

children can also withdraw themselves from the study at any time. You can also withdraw all the video footage of your children and information gathered on your children at any time. You and your children can ask for the recording to be stopped at any time.

Only my supervisors and I will have access to the information gathered. Names will be changed in the resulting report and the report will not contain any identifying details. The results of the research may be published but the data gathered, including the videotaped material, will be kept completely confidential.

The project has been reviewed and approved by the University of Canterbury Human Ethics Committee.

**Who do I contact if I have any concerns or questions about this study?**

If you have any questions about the study please do not hesitate to contact me, Suzanne Neame, at 03 3499764 or my supervisor, Karyn France at 03 364 2610.

**Suzanne Neame**  
**Postgraduate Student**  
Ph: 03 3499764  
[smn15@student.canterbury.ac.nz](mailto:smn15@student.canterbury.ac.nz)

**Project Supervisor: Karyn France**  
Ph: 03 364-2610  
Internal Phone: ext 6610  
[karyn.france@canterbury.ac.nz](mailto:karyn.france@canterbury.ac.nz)

## Appendix C

### Information Letter for TD Siblings



**School of Educational Studies and Human Development  
University of Canterbury**

#### Helping children to play with their siblings on the autistic spectrum

#### **Information Sheet for Child Participants** (to be presented orally)

Dear .....

Hi, my name is Suzanne Neame. I am learning about how to make it easier for big brothers and sisters to play with their little brother or sister with special needs. Sometimes children with special needs can be fun to play with and sometimes they can be difficult to play with. I want to give some big brothers and sisters help in ways that will make it easier to play with their little brother or sister.

If you would like to learn how to make it easier to play with ....., I will meet with your parent (s) . We will talk about how I could help you learn ways to play with ..... You and your parent(s) will be able to ask me questions about what we would do. I will ask you some questions about playing with ..... If you do not want to answer a question, you can say “I do not want to answer that question” and no one will be cross with you.

I will come to your house sometimes and video you and .....together to learn how you usually play together. After that, I will come to your house two times a week for 7 weeks and each time you and I will spend some time ( ten minutes) doing things together. We will watch some of the videos of you and ..... to help us work out what kind of



things make it easier for you and ..... to play together, we might look at some books together, and we will play some fun games. Then I will video you and .....together again.

When I have come to your house a lot of times we will make a video of your favourite bits of the videos of you and .....together. The video we make will be your video to keep.

I will be writing my work up for the University but it won't have you or your family members' names in it and the videos I will make of you and ..... will only be used to help us work out ways to make it easier for you and ..... to play together. Any time you want to you can tell me to stop videoing you, you can stop helping me with my work any time and you can tell me not to use the video recordings and information I have on you and your family in my work.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee.

**Suzanne Neame**  
**Postgraduate Student**  
Ph: 03 3499764  
[smn15@student.canterbury.ac.nz](mailto:smn15@student.canterbury.ac.nz)

**Project Supervisor: Karyn France**  
Ph: 03 364-2610  
Internal Phone: ext 6610  
[karyn.france@canterbury.ac.nz](mailto:karyn.france@canterbury.ac.nz)

## Appendix D

### Parent Consent form



School of Educational Studies and Human Development

University of Canterbury

### Helping children to play with their siblings on the autistic spectrum.

#### Parent Consent Form

I have read and understood the description of the above named project. On this basis I give consent on behalf of \_\_\_\_\_(my daughter/son) and on behalf of \_\_\_\_\_(my daughter/son) to participate in this project. I understand that if the researcher Suzanne Neame feels it is necessary, she will seek my consent to speak with other professionals who are involved with my son/daughter on the Autistic Spectrum.

I consent to publication or presentation of the results of the project with the understanding that anonymity will be preserved.

I understand also that I may withdraw my children from the project at any time, including withdrawal of any information that has been provided.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee

NAME ( please print)

Signature:

Date:

## Appendix E

### Parent Consent to the Researcher Contacting Professionals Involved with the Children

School of Educational Studies and Human Development  
University of Canterbury



#### Helping children to play with their siblings on the autistic spectrum.

#### Parent permission to consult with others involved in their child's care

I understand that the researcher, Suzanne Neame, feels it is necessary to speak with \_\_\_\_\_ who works for \_\_\_\_\_ and is involved with my son/daughter in their capacity as a \_\_\_\_\_. Suzanne has explained to me that she will be seeking information on my son/daughter's developmental status, strengths and needs. I consent to Suzanne's speaking with \_\_\_\_\_ to gain this information on my son/daughter \_\_\_\_\_.

This project has been reviewed and approved by the University of Canterbury Ethics Committee.

NAME \_\_\_\_\_ (please print):.....

Signature:

Date:

## Appendix F

### Child Consent Form



School of Educational Studies and Human Development  
University of Canterbury

### Helping children to play with their siblings on the autistic spectrum.

#### Child Consent Form

The following information will be read with, or to the child:

1. Suzanne has talked to me and asked me if she can work with me on ways to make it easier for me to play with..... I understand that Suzanne will ask me some questions and to watch some video of me and .....with her. I understand that Suzanne may also ask me to play some games, read some books with her, and to talk about ways of playing with.
2. I understand that I do not have to do or say anything I don't want to.
3. If I change my mind at any stage, I can stop and I can tell Suzanne to stop videoing at any time.
4. When we have finished, Suzanne and I will make a video of my favourite bits in the videos she has taken of me and ..... The video will be mine to keep.
5. Suzanne will be writing a report about her work with me but she will not use my real name.

This project has been reviewed and approved by the University of Canterbury Human Ethics Committee.

I agree to take part in this project.

Name (please print) \_\_\_\_\_

Signature:

Date:

## **Appendix G**

### **Personality Profile**

**Name:**

**Nick Names:**

#### **Interests and Hobbies**

What are some of the things that you enjoy doing?

What do you dislike doing?

#### **Family**

What things do you enjoy doing with your family?

What things do you enjoy doing with your brother?

#### **Friends**

Who are your friends?

Why do you like them?

What do you do with your friends?

### **School**

What do you think of school? What do you like best/least? What do you think you are good at? What do you find difficult?

### **Food**

What is your favourite food? What do you not like eating?

### **My favourite day**

If you were told you could do anything you wanted all day, what would you choose?

### **My unhappy day**

What might you be asked to do that would make a day unhappy?

### **What makes you laugh?**

### **What makes you sad**

( adapted from personality profile – my view – the friendship formula -2008 Alison Schroeder)

## **Appendix H**

### **Personality Profile**

**Name:**

**Nick Names:**

**Interests and Hobbies**

What are some of the things that your brother enjoys doing?

What does he dislike doing?

**Family**

What things does your brother enjoy doing with your family?

What things do your brother enjoy doing with you?

**Friends**

**Who does he like?**

**Why does he like them?**

**What does he do with his friends**



**School /Preschool**

What does he think of school? What does he like best/least? What do you think you he is good at? What does he find difficult?

**Food**

What is his favourite food? What does he not like eating?

**His favourite day**

If he was told he could do anything he wanted all day, what would he choose?

**His unhappy day**

What might he be asked to do that would make a day unhappy?

**What makes him laugh?****What makes him sad?**

( adapted from personality profile – my view – the friendship formula -2008 Alison Schroeder)

## Appendix I

**Table 2**

### Activities Introduced to the Children During the Intervention

Activities	Description
Scrapbooks and “myself” and “my brother forms”	All the girls liked filling in the forms about themselves. Filling in the forms gave them an opportunity to talk about their lives. Filling in their forms and their brother’s led to the identification of similarities between themselves and their brother. Forms adapted from forms in “The Friendship Formula” Schroeder (2008).
Spider and web game	Spider web (made with a hoop) , Insect cards, Players take an insect card. Player with the spider card counts to 50 while the holders of the other insect cards hide. The player with the spider card takes the web and when the player finds another player, they put the web over their head. This game was designed to support children with ASD in playing hide and seek.
Snap	Played on a blank game board with a line down the middle to define areas for players.
Making bread	Dough was provided so that the children could knead , shape and bake the dough
Gluing and cutting out	Paper, glue pens, pictures to cut out, pencils and a board with a line down the middle to rest the paper on was provided.
Trains and fairies	Bingo type game. The numbers one to six were painted on two sides of a board with a line down the middle. The children were given cards based on their interests ,eg trains and fairies, with which to cover the numbers when they threw that number on the dice. The game was designed to encourage turn taking and was based on a game in Beyer & Gambletoft “ Autism and Play” (2000)
Ribbon sticks And dance music	Identical sticks with 1 metre of colourful ribbon attached. Instrumental dance music.
Identical balls	Children were provided with 2 identical balls. Cones were also provided.
Feelings game	Game from the “Friends for life workbook for children” (Barrett, 2004). The game involves one person miming a feeling and the other person guessing what feeling they were miming.

## Activities Introduced to the Children During the Intervention (continued)

Activities	Description
Books using the children's favourite characters	These books detailed the children's favourite characters playing the games that had been introduced to the children. Books included a book on Postman Pat and Fireman Sam playing with identical balls. The Bernstein Bears playing hide and seek with soft toys. Tigger and Piglet using ribbon sticks to play the limbo. Postman Pat and Fireman Sam play "Guess Who"
Face paints	Based on a suggestion in Beyer & Gemmeltuft (2000) . The intention was for both siblings to paint their faces and each other's face.
Play dough	
Role plays	Puppets were provided and scenes were selected from the video footage of the children playing together.
Hide and seek with soft toys	Children's toys were hidden and they were encouraged to find their toys together.
Guess Who	Board game by Hasbro.
Two identical sets of musical instruments	There were about 5 different types of instruments – clappers, drums, triangles, tambourines and shakers
My Family Books	Based on an idea in Harris and Glasberg (2007). The TD children were encouraged to compile books about their families using photos.
Balloons	Multi coloured balloons
Memory game	Cards made from photos and pictures of the children's interests eg fairies and trains.

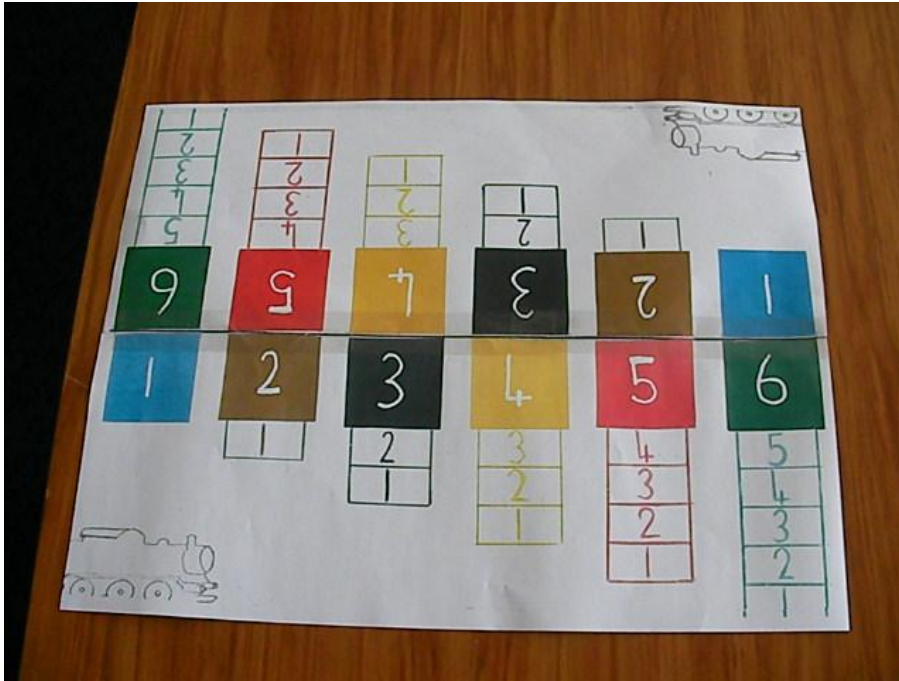
## Appendix J

### Resources

- Coulter Video (Producer) & Coulter, D (Writer/Director) (2007). *Understanding Brothers and Sisters on the Autism Spectrum.*( documentary). United States: Coulter Video
- Dunbar, P. Ely, L. (illustrator) (2004). *Looking after Louis.* London : Frances Lincoln, 2004.
- Greive, B.T. (2005). *The blue daybook for kids: A lesson in cheering yourself up.* Australia: Random House.
- Edwards, B., Armitage, D (illustrated) (1999). *My brother Sammy.* London: Bloomsbury Children's Books
- Hoopmann, K. (2006). *All cats have asperger syndrome.* Jessica Kingsley: London.
- The Autism Society of America. *Growing up together: A booklet about friends with autism* [brochure]. Maryland: Author
- The Autism Society of America. *Sibling perspectives: Guidelines for parents* [brochure].Maryland : Author
- Thompson, M. (1996 ). *Andy and his yellow frisbee.* Rockville MD: Woodbine House

## Appendix K

### Train and Fairies Game



Board designed by Clare Cudmore-Neame

#### Equipment

One dice

Two sets of six cards with numbers and colours to match board. There are a number of options of sets of cards

( different coloured fairies, different coloured trains, piggy banks etc)

Board

#### Instructions

Each player shakes the dice. They place the card with the same number as shown on the dice, on the matching number on the board if they have not already done so. They then pass the dice to the other play. The winner is the first player to cover all the numbers on the board.

## Appendix L

**Table 3**

**Parents answers to post-project scaling questions**

<b>Questions : 1 to 5 scale</b>	<b>Sibling dyad 1</b>	<b>Sibling dyad 2</b>	<b>Sibling dyad 3</b>	<b>Sibling dyad 4</b>
How much did the children play together pre project?	2-3	2	4	4
How much do they play together post-project?	3-4	2-3	3	4
How much did the older child appear to enjoy playing with the younger child pre intervention?	1-2	2	1.5	3
How much does you older child appear to enjoy playing with their younger sibling post project ?	2-3	3	4	3+
How much did your younger child appear to enjoy playing with the older child pre-project?	3	5	1	4-5
How much does your younger child appear to enjoy playing with the older child post –project?	3-4	5	4	4-5
How much, if any, has the understanding of the older child of their younger sibling’s difficulties increased?	4	5	4	3-4